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ABSTRACT

This report of a congressional subcommittee hearing focuses on the status of day care programs for the elderly. Opening statements by subcommittee members consider the need for programs, costs, government involvement, and abuse of the elderly. Summarized statements by witnesses examine the value of various day care programs as alternatives to nursing homes. A panel of witnesses presents family histories of elderly parents and their experiences with day care: one panel member describes his own participation in a day care program. Findings from a study on the costs and effects of adult day care conducted by the National Center for Health Services Research are presented, and the differences between health-oriented day care and social day care are discussed. The status of adult day care in Massachusetts and Washington is outlined by two witnesses: programs and costs are also reviewed. Testimonies by directors from various models and day care programs are included along with statements from a panel of administration spokespersons. The appendix contains additional statements and an extensive conference report on adult day health care. (NRB)

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ADULT DAY CARE PROGRAMS

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HEARING
BEFORE THE
SUBCOMMITTEE ON
HEALTH AND LONG-TERM CARE
OF THE
SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES
NINETY-SIXTH CONGRESS
SECOND SESSION

APRIL 23, 1980

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ADULT DAY CARE PROGRAMS

WEDNESDAY, APRIL 23, 1980

U.S. House of Representatives,
Select Committee on Aging,
Subcommittee on Health and Long-Term Care,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:08 a.m., in room 210, Cannon House Office Building, Hon. William R. Ratchford (acting chairman of the subcommittee) presiding.

Members present: Representatives Ratchford of Connecticut, Biaggi of New York, Bonker of Washington, Ford of Tennessee, Drinan of Massachusetts, Oakar of Ohio, Ferraro of New York, Mica of Florida, Abdnor of South Dakota, and Evans of Indiana.

Staff present: Louise Bracknell, staff director; Mark Covall, research assistant; Hazel K. Edwards, secretary; Eleanor Hall, intern; Larry R. Parkinson, minority staff director; and Glenda Barnhill, staff assistant.

OPENING STATEMENT OF CHAIRMAN WILLIAM R. RATCHFORD

Mr. Ratchford. Ladies and gentlemen, we will be starting shortly, as you have just heard the buzzers ring. There is a rollcall in the House of Representatives, so the members of the panel will have to go over to vote and come back.

Senator Pepper, unfortunately, is sick with a cold and will not be in today. He wanted to come in, obviously, because he is a great supporter of day care. His detailed statement will be submitted for the record, and he assures you of his continuing, ongoing, and strong support for day care.

[The prepared statement of Chairman Claude Pepper follows:]

Opening Statement of Chairman Claude Pepper

It is my pleasure to convene this hearing—the first congressional hearing devoted exclusively to an examination of day care for the elderly.

By all accounts adult day care is an idea whose time has come. In 1974, there were only some 15 programs in the United States. Today, there are over 600. This rapid growth has come about without federal policy, without a mandate to the states, and without a unified funding source.

In my book, this qualifies adult day care as something of a phenomenon: What created the momentum for this kind of expansion? I believe the answer is that day care grew from grass roots—with community efforts responding to community need.

Popular opinion would have us believe that many American families don't care about their elders—that they are content to dump their mothers and fathers and aunts and uncles into institutions and leave responsibility for their care to others. That kind of mentality is dangerous, and it's misleading.

The fact is that most American families don't have the resources to provide 100 percent of the care an impaired older relative might need to stay out of a nursing home. The complexities of our increasingly mobile and impersonal society make it difficult to keep a household running smoothly.

The needs of an impaired older relative who requires special care can compound the difficulties. For lack of alternatives, this situation far too often results in nursing home placement.

This does not mean that families don't wish to care for their elderly. To the contrary, it often means that all other doors are closed. We want to open those doors. Our Committee has devoted years of work to making home health care available to the elderly. Our task is by no means completed, but we have achieved considerable progress. Home care and day care should go hand-in-hand as components of a continuum of community-based care for the elderly.

In our hearing today, we want to learn what day care means to families. We want to know how the various programs work. We want to discuss the costs of day care. And we want to know exactly what the Federal government is doing in this area.

A principal concern has been the lack of policy focus in day care. Some 16 potential sources of funding have been identified. We have distributed a survey to all the states which we hope will prove beneficial in getting a better idea of the extent of day care around the country.

Encouraging day care does not just mean new dollars It might mean a reorganization of the haphazard financing structure. We know that of the 600 programs in existence now, well over 300 receive Title XX Social Service funds; over 100 receive funds under Title III of the Older Americans Act, and 125 receive reimbursement under Medicaid. The remainder of day care support comes from a hodge-podge of public and private sources, area agencies on aging and others. Moreover, a large number of persons—as many as one-half of the participants in some programs—pay their own way.

We have much to learn today. I want to welcome each of you to this hearing. We are especially pleased to have with us a number of members of the National Institute on Adult Day Care of the National Council on the Aging. Your concern and your expertise are welcome, and I want to encourage you to work with out Committee in the development of long-term care policies which will enhance the lives of elderly Americans now and in the future.

Mr. RATCHFORD. I am Congressman Bill Ratchford, Congressman from the State of Connecticut. I will be chairing this morning's portion of the hearing.

[The prepared statement of Chairman William R. Ratchford follows:]

PREPARED STATEMENT OF CHAIRMAN WILLIAM R. RATCHFORD

Mr. Chairman, I applaud the efforts of yourself and the fine staff of the Subcommittee on Health and Long-Term Care in conducting today's hearing on day care for the elderly.

As you well know Mr. Chairman, I served as Commissioner for a cabinet-level Department of Aging in Connecticut just prior to my election to the Congress last year. Preceding that appointment, I served as Chairman of the Governor's Blue Ribbon Committee to Investigate the Nursing Home Industry in Connecticut. As part of the Commission's outstanding report completed in December of 1976, the Subcommittee on Alternatives to Institutionalization recommended that state policy and funding should be directed towards providing a continuum of care for the elderly. Services should range from simple support services enabling a minimally impaired person to live at home independently through skilled nursing care in an institutional setting, through comprehensive skilled nursing care in an institutionalized setting.

Adult Day Care was identified as one attractive option along this continuum of care, which would prevent the inappropriate institutionalization of many elder people and offer a more humane social, medical and economic alternative. Equally important, day care could provide critical social and economic support to family members who care for their other relatives. Far too often, Mr. Chairman, older people are forced to deplete their limited financial resources in paying for their social and health care needs not covered by Medicare. To be eligible for those support services provided under Medicaid, almost all of their resources must be "spent down". As a result of depleted financial resources and clearly lacking support services in the community, many older persons are left no alternative but to accept placement in a nursing home as a Medicaid recipient.

The time is now to identify a place in the continuum of care for adult day care. In my state of Connecticut we have estimated that 14 to 17 percent of the community-based elderly suffer from chronic conditions which limit the performance of major activities of daily living. The socialization and multiple services and therapies available through day care centers can help many of these elderly persons live independently at home or under the care of family members.

In 1978, the Connecticut Legislature appropriated $70,000 for the establishment of a model adult day care program in southeastern Connecticut. Serving 18 towns, this program began operation in December of 1978, and has provided transportation, nursing, rehabilitation, recreation, counseling and nutrition services to elderly persons with a high probability of being institutionalized. Along with mandating this project, the legislature gave the Department on Aging the responsibility for evaluating this and other programs in the state. This evaluation culminated last September with the submission of comprehensive recommendations to the Legislature on the future role of adult day care services in the state.

This landmark report included several important findings. The full public cost of adult day care was compared to the total public cost of chronic and convalescent nursing homes (SNF) on the average. Estimates for adult day care reflect actual program expenses, net daily living expenses of the client based on Bureau of Labor Statistics figures, and the cost of other services rendered for the participant. The results of this comparison are revealing indeed, Mr. Chairman. Total public costs of the adult day care program were calculated at $113.87 per client in weekly expenses and a per diem of $16.27, as opposed to a weekly expense of $228.00 per client and a per diem of $32.57 for skilled nursing facility costs. Additionally, this study represented the first empirical analysis of its kind on the impact of adult day care on the caring family. Participant families experienced reductions in family stress and tension and the program appears to have had a most favorable impact on the quality of the older person's life.

Thus, it seems quite clear that if day care is focused on those with a high probability of institutionalization and is fully utilized, that it can be extremely cost-effective. In fact, the Connecticut experience would indicate that even if only 60 percent of adult day care clients would have otherwise been institutionalized, adult day care would still be a cost-effective alternative to institutionalization. The evidence evaluated in my own state seems decisive, and I am pleased to report that there are now some 17 adult day care programs in Connecticut and the state legislature's Appropriation Committee last week passed a bill that would require the state's Medicaid administering agency to amend its plan to include coverage for adult day care services. Also the state's Title XX plan has been released for review, and for the first time includes provisions for the targeting of adult day care activities.

Great progress has been made in identifying the advantages of adult day care, and I am eager to hear from today's witnesses on the experience in other states. This exciting new concept can work and certainly warrants greater attention and funding support from the federal government.

Thank you.

Mr. **Ratchford**. Briefly, by way of background, I was Connecticut's commissioner on aging for 2 years. Prior to that, for 1½ years I chaired Connecticut's investigation of nursing homes, and in both capacities we found that there should be a continuum of care; that that continuum of care certainly should include day care.

We have found, for example, that the day care experience in Connecticut costs $113.87 a week, versus skilled nursing care costs substantially above and beyond that at a weekly expense of $228 a week. So from the point of view of humanity, and from the point of view of economics, and from the point of view of providing a continuum of care, we in Connecticut have found it to be an experience that we want to encourage. We are encouraging it through our State funding. We are encouraging it through our medicaid provisions. We are encouraging it through title XX, and we will have more detail on it later this morning.

With me is a Member of Congress from New York, Geraldine Ferraro. She will be back as soon as we vote, at which time the meeting will officially begin. Thank you. We will go over and vote, and come back immediately.

[The subcommittee recessed at 10:10 a.m.]

Mr. **Biaggi** [presiding]. The hearing is called to order. I will preside for a few moments until Mr. Ratchford returns. Mr. Ratchford has just returned.

Mr. **Ratchford**. It should be an hour or so before there is another rollcall, so we should be free to proceed.

Again, I am Congressman Ratchford, from the State of Connecticut. Chairman Pepper is at home with a cold. He regrets that he cannot be here. He is preparing himself for the budget debate, which you know full well is extremely important as it relates to programs for the aged. There are other members of the panel, and other Members of Congress who would like to be recognized. Before we adjourned, I was prepared to recognize a Member of Congress from New York, Geraldine Ferraro, for her statement.

Ms. **Ferraro**. Thank you, Mr. Chairman. I will defer to my colleague from New York who has to go to another committee meeting which he will be chairing.

Mr. **Ratchford**. The Chair then recognizes someone I am sure you all know, a Member of Congress from New York, someone who has been extremely active in the area of aging, someone who is always on the floor working for programs to improve the life of the aging, Mario Biaggi, from New York. Mr. Biaggi.

STATEMENT OF REPRESENTATIVE MARIO BIAGGI

Mr. **Biaggi**. Thank you very much, Mr. Chairman, thank you for indulging me.

I simply feel compelled to make my comments this morning in the light of recent events. I would like to stay on, but I am chairing another committee hearing in the Longworth Building, and we are in the middle of receiving testimony from witnesses who have traveled from many parts of the country to testify. Last Monday, as chairman of the Subcommittee on Human Services, I conducted a hearing in the city of New York. That meeting was attended by Ms. Ferraro, Mr. Luken, Mr. Rinaldo, and other members of the committee. We dealt with the issue of domestic violence against the elderly.

You may have read about the issue in the New York Times, or other papers, or perhaps have seen segments about it on the electronic media. Unfortunately, the fact of the matter is it is not an uncommon event. The University of Rhode Island has revealed in its studies for instance, that there are at least some 500,000 such incidents during the course of 1 year. Some people feel that the incidents may be even greater in number. At the hearing in New York we had the advantage of two witnesses who were victims, and the testimony of a police officer who handled a case of another, a victim. All of their testimony was graphic, and one was terribly, terribly repulsive. This particular woman was assaulted repeatedly by her 36-year-old grandson with a part of the wheelchair in which she was bound. She was semiparalyzed, and she was robbed. In addition to that, she was sexually abused. But it was not a single event. It had happened many times, before. This particular episode had a unique development because a witness, not the victim, testified. As a result of this, the assailant was committed to the penitentiary for 3 to 7 years.

If we did not have the witness, there is every reason to believe the offense would have continued. I say this because the one common element that runs through all of these cases is that the victim is reluctant to prosecute. This occurs for a number of reasons: One, fear of reprisal; and two, the ties of relationship. The victim undoubtedly has more affection for the offender than the offender has for the victim.

The abuse occurs in several ways; including psychological; physical, and financial. In fact, robberies occur; and the prospect of being put out of a home and put into an institution is a real threat.

Another witness testified that she was put out of her home repeatedly and would have to sneak into the house while the others were asleep. She was tortured, and was visited regularly when she received paychecks. They would come, take the checks, and abuse her physically. Apparently there was a long history of this occurrence.

I raise this today because one way to deal with the problem is to expand adult day care services. I point this out to you because there is a definite linkage between the offense and the remedy. Hopefully, by virtue of these hearings that we will give this problem the same visibility that child abuse now has.

Some 10 years ago, when I came to Congress, I dealt with the issue of child abuse. Child abuse was relatively obscure then. Today it is no longer. I do not think it will take 10 years for this issue to get the kind of attention it requires, but it does require the total commitment, and participation of the entire aging network, and people in public life. So far, the response has been surprisingly large, and the reaction has been gratifying. We anticipate future hearings in different parts of the country for the same purpose, but I offer the expansion of the adult day care program as a possible remedy to the problem. I do not believe that anyone would argue over the benefits of a day care program. However, it becomes more urgent when you consider that it can diminish the number of offenses that we find occurring in the home.

Thank you very much, Mr. Chairman, for indulging me. If I may, I would like to insert my prepared remarks at this point.

Mr. RATCHFORD. Thank you very much, Congressman Biaggi. Without objection, your statement will appear at this point in the record.

[The following was received for the record:]

PREPARED STATEMENT OF REPRESENTATIVE MARIO BIAGGI

I would like to commend my most distinguished colleague in congress, Claude Pepper for conducting this very important hearing on the effectiveness of adult day care. It is yet another clear example of his genuine concern and long-time efforts on behalf of the elderly citizens of our nation.

I serve as the chairman of the Subcommittee on Human Services of the House Select Committee on Aging. On Monday, in this capacity, I conducted a hearing on a matter which has great bearing on the subject at hand today—I speak of the national scandal of domestic violence against the elderly.

Researchers have identified four major forms of domestic violence against the elderly. They include the following:

Physical abuse.—This includes direct beating and the withholding of care, food, medicine, and supervision.

Psychological abuse.—Including verbal abuse and threats.

Material abuse.—theft of money or personal property.

Violation of rights.—Forcing older persons into nursing homes.

On Monday, the committee learned through testimony that acts of physical violence against older persons are often directly related to the lack of periodic respites for an overburdened caregiver. Shouldering the full responsibility for an ailing parent without the benefit of external or community supports can arouse feelings of an entrapment on the part of the adult child who sees no avenues of relief. When pressures are high, this kind of tension can precipitate acts of violence by a frustrated caregiver.

While adult day care in and of itself is not the Alpha and Omega to solving this problem, it is a partial solution which should be given very serious consideration.

If the pressures of such a full-time responsibility can be alleviated by the introduction of adult day care, then these services can help to prevent the harmful build-up of stress and thereby diminish the incidences of domestic violence against the elderly. In short, adult day care can contribute a long way to the maintenance of healthy intergenerational living arrangements.

The committee did receive specific recommendations by numerous individuals urging the expansion of adult day care. I wish to lend my support to this most important effort and sincerely hope that recognition of the need for the expansion of such services will be adopted on a national scale very soon.

Mr. RATCHFORD. The Chair now recognizes the ranking minority member of this committee, James Abdnor, from South Dakota, who has a statement that he would like to present this morning.

STATEMENT OF REPRESENTATIVE JAMES ABDNOR

Mr. ABDNOR. Thank you, Mr. Chairman.

I find myself somewhat in the same position as Mr. Biaggi. One of my other committees is marking up a very important piece of legislation that affects my State, so I too, will be going back and forth today, between several hearings.

I am pleased to be able to participate in today's hearing, for there is a tremendous need in this country to develop community-based long-term care programs, and adult day care promises to be a very important part of our effort in this area.

It has been estimated that approximately 8.5 million noninstitutionalized older Americans are restricted in performing certain basic activities, including about 4 million who are severely limited due to chronic illness. In addition, there are many individuals currently residing in nursing homes who could return to the community if appropriate support services were available. Simply said, there are millions of elderly Americans crying out for community services.

The growth of adult day care programs in this country has been phenomenal. Only 6 years ago, fewer than 15 programs could be identified. Now there are over 600. Perhaps the most amazing aspect of this expansion has been the lack of any direct Federal initiative in the adult day care area. The programs have been developed at the grassroots level in response to local needs.

Before we advocate a broad expansion of the Federal role in adult day care, there are some difficult questions which we need to answer. The first and foremost question is, what do we mean by adult day care? There is a great deal of confusion, even in the aging community, over the many definitions of day care. Are we talking about principally medical programs, social programs, or a combination of the two? Who are we trying to serve with adult day care—only the impaired elderly? If so, how impaired do they have to be?

I fully support the development of a flexible range of noninstitutional community care services, but I am fearful of building another layer of aging programs which would further dilute the already limited funds for elderly services. Adult day care hold a great deal of promise, but it is essential that it is developed in conjunction and in coordination with existing programs, such as multipurpose senior centers. As one more component in a continuum of care, day care will be extremely valuable to older individuals and their families.

I would like to offer one final caution. One of the complaints we have heard most often during our day care discussions is that there is no Federal thrust, and no uniform standards in the area of adult day care. Do we really want to increase Federal controls? Certainly the Federal Government has a stake in day care since it provides much of the financial support. On the other hand, I suspect that one of the reasons day care programs have expanded so much in the last few years is because there has been flexibility at the State and local levels. There is probably a need to coordinate funding sources, but I seriously question the concept of uniform Federal standards at this time.

We have an exciting group of witnesses here today, and I hope they will be able to shed some light on these questions.

Thank you, Mr. Chairman.

Mr. RATCHFORD. Thank you very much.

Already introduced before the rollcall, a Member of Congress from New York, Geraldine Ferraro, with a statement.

STATEMENT OF REPRESENTATIVE GERALDINE A. FERRARO

Ms. FERRARO. Thank you, Mr. Chairman.

Largely through the efforts of this committee and its Chairman, Senator Pepper, this Nation has become aware of the folly of the wholesale institutionalization of our Nation's elderly. Studies have indicated that many nursing home residents are inappropriately placed. Too often institutionalization is seen as the only alternative as families struggle with the difficult question of how to care for their senior citizen relatives.

The General Accounting Office, in a report dated November 26, 1979, indicated that a large percentage of the elderly being cared for in nursing homes were there, despite the fact that their basic requirements were nonmedical supervision and management. The GAO concluded that placing senior citizens in nursing homes, even when they have the potential to remain in the community is problematic because, one, it is contrary to the wishes of most elderly and their families; two, individuals may be provided a more intensive level of care than actually needed; and three, it requires a costly outlay of public and private funds, and is an inefficient use of this service.

Though I am not a member of this subcommittee, Mr. Chairman, I asked that I be able to make this statement and sit with the committee because of my deep concern about the issues raised by unnecessary institutionalization and the need to find alternatives to it. Like most people who are involved with the field of aging, I am convinced that the unnecessary institutionalization of our senior citizens wreaks havoc.

The human costs, attributable to inappropriate nursing home placement are immeasurable. In many cases we merely sentence our elderly to death, and I may add, a death which is without either dignity or comfort.

On Monday, as Congressman Biaggi indicated before, I participated in hearings in New York City on the subject of intrafamilial violence against senior citizens. Over and over again the witnesses expressed the belief that if there were alternatives to keeping senior relatives at home around the clock, the tensions and pressures which result in domestic violence against grandparents would be alleviated. This is just one area in which evidence strongly indicates that by allowing senior citizens to remain in an intergenerational setting, but by also providing for a brief break on a daily basis, we can avoid both institutionalization and the horror of domestic violence.

Dostoevski once said that "You can judge the quality of a civilization by the way it treats its children and its senior citizens." I would hope that modern America is not judged by that standard, but if we are to be, I think we have time to have the sentence commuted by early action on proposals such as senior day care.

I commend the chairman for calling these hearings. I am grateful for the opportunity to participate in them. I know that the witnesses here today will reinforce that which the committee already knows, that there are alternatives to the wholesale institutionalization of our elderly, and that by providing them we will be strengthening not only the will and dignity of our elderly, but our entire society.

As I mentioned earlier, I will be unable to remain for the morning. I am also on the same committee as Mr. Abdnor. We are marking up an important piece of legislation; however a member of my staff, is going to remain. We have had an inquiry in our district for a senior day care center, and I am sure that she will find some answers today which we will be able to pass on to the applicant.

I thank Mr. Chairman for the opportunity to make my statement.

Mr. RATCHFORD. We thank you very much, and all of the statements thus far will be made a part of the record, including the statement that Chairman Pepper would have delivered, and the statement that I summarized before the rollcall occurred.

At this point I would like to recognize another very active member of this committee, and this committee has been active here and on the floor, Congressman Dan Mica, of Florida.

STATEMENT OF REPRESENTATIVE DAN MICA

Mr. MICA. Thank you, Mr. Chairman.

I would just like to make a brief comment and associate myself with the comments of my colleague from New York, Ms. Ferraro.

I might say that being from Florida, which is becoming a retirement State, and seeing the progression in average age, we know that we have to look for alternative solutions. Until this point, until recently, we have only had a few solutions, one, to stay at home; or two, nursing home care. This is a new alternative. It is a fresh idea and a new approach, and I am most interested in following the hearings, listening to the testimony, reading it—I will not be able to stay either—and hopefully we can come up with some suggestions that will provide some new hope for those in advancing years, and those of us who have parents of that age.

Thank you, Mr. Chairman.

Mr. RATCHFORD. We thank you, and your statement will be made a part of the record.

At this point, if there is no objection, I would like to submit the prepared statement of Congresswoman Oakar for the hearing record. Hearing no objection, it is so ordered.

[The prepared statement of Representative Mary Rose Oakar follows:]

PREPARED STATEMENT OF REPRESENTATIVE MARY ROSE OAKAR

I would like to thank the Members of the Subcommittee on Health and Long Term Care for letting me listen to the valuable testimony of the witnesses who have appeared today. Hearings like this are needed to explore all possible areas in the care of the Elderly.

Today we have heard witnesses speak on their experiences with Day Care for the Elderly. Day Care of this type is in its' infancy. The people who have talked to us today are among this nations' innovators and they are to be commended. Because a great number of problems face Adult Day Care, there will be differences of opinion and contradiction, but this is to be expected with any new and emerging concept.

On one hand we have had testimony from Dr. William Weissert, who concludes that Adult Day Care is an add-on service, does not prevent institutionalization, and is not cost-effective. On the other hand, his research does not dispute the facts that the program provides more independence for older people, that it provides relief for care providers, and it relieves the loneliness of many old people. It is hard to put a monetary value on these benefits that are so vital to our nation's elderly.

No researcher is expected to find answers to every question and no study is supposed to be accepted without corroborating evidence. Dr. Weissert himself has stated that there is a strong need for more research in this field. Across the nation there are over 600 active programs, and we have heard the testimony by directors of a few of the more outstanding programs. Through years of experience these directors have conducted programs that provide multi-faceted treatments and benefits. It is refreshing to see communities, philanthropic organizations, and governmental bodies working in coordination to get new initiatives moving and to keep successful programs funded. These program directors have developed centers which have a realtively low cost, that result in significant savings when compared with institutionalization. They have developed inventive and flexible variations to meet the needs of their particular communities.

Most promising are the prospects for the future. We may find that Adult Day Care is effective as a Half-way house to remove people from institutions who need only marginal health care. It is also possible that Day Care could be used in a preventative manner to deter or at least delay institutionalization of some older Americans. Both of these prospects make sound economic sense, and also provide the chance for independence and dignity that this nation's elderly deserve. These witnesses as well as the participants, and families are sending us a message. Because these Centers have evolved on their own, they truly represent the needs of the seniors and the communities. Through this hearing I hope that they realize that we in Congress are interested in their progress. It is now up to us to see what we can do to make it easier for new programs to start, and to help the existing programs to continue and expand.

Mr. RATCHFORD. We notice the presence of television, and under rule 17, these proceedings may be covered by television. I simply would note that for the record.

At this point I would like to call to the chair an individual who has been active on this committee for a long period of time, an individual who has brought witnesses here this morning, and someone who has devoted a great amount of effort to improving the plight of the elderly, not only in his home State of Washington, but throughout the United States, the Honorable Don Bonker. Don.

STATEMENT OF REPRESENTATIVE DON BONKER

Mr. **Bonker**. Thank you, Congressman Ratchford.

I would like to commend the chairman of the committee, Mr. Pepper, for once again bringing before our attention a timely and important issue at this time as it relates to adult day care services for elderly Americans.

On the second panel we have witnesses from Washington State, Mr. Charles Reed, who is one of the leaders in this area, and certainly has done a fine job in my State of Washington; and also Mr. Bill Weissert, from the Department of Health, Education, and Welfare, who has just completed a study on the cost effectiveness of adult day care services in places where they are being provided.

This issue will represent something of a dilemma for me because I recognize and fully appreciate the work that is being done by the state of Washington, but I also feel that Dr. Weissert has raised some valid questions and I think deserve the full attention of this committee.

We ought to be looking at such things as to whether day care services are the best possible use of our scarce resources for health care services. We ought to be looking at whether the use of our health care budget for this purpose is duplicating other services, particularly those that relate to comprehensive health care. Further, we should absolutely make sure that the services that are being provided are indeed going to needy people, those whose needs are not being met currently by existing services.

And finally, "How do the social day care programs differ from senior citizen centers, and could those senior centers be slightly modified so that they can serve any needs that are now met?" I am hopeful that the potential of these programs will be achieved in a way that will not duplicate existing programs, and will be cost effective. To be less expensive, my guess is that they will have to be a substitute for nursing homes, or hospital care. If that is the case, then this committee certainly should look at the concept.

At this time we would like to call the first panel persons that are on our schedule, and they include Mrs. Joanne Jackson Yelenik and Mr. Horace Woods and Dr. Paul Feng.

We will then begin with Mrs. Yelenik, and I would ask that each of the witnesses identify themselves and their professions, and then proceed hopefully with a summarized statement, and their full statement will be included in the official record.

STATEMENT OF JOANNE JACKSON YELENIK, TEACHER, GEORGETOWN DAY HIGH SCHOOL, WASHINGTON, D.C.

Mrs. **Yelenik**. My name is Joanne Jackson Yelenik, and by profession I am a teacher at Georgetown Day High School here in Washington, D.C. I am here to relate some of our family history which relates to matters on which the committee is meeting. I am submitting to the committee, along with a copy of my oral statement, the following items: Documents relating to our family history with social and medical care services; an 11-point suggestion for legislation written in a letter to Congressman Michael Barnes on March 16, 1980, and submitted also to this committee; a copy of a law passed in January of this year by the State legislature of California seeking to address and rectify the prejudices of financial aid and medical insurance as they affect sufferers of chronic brain damage related illnesses; a book review of a book entitled, "Unloving Care" which explores the ineffectiveness of nursing home care facilities and the extent to which this kind of care is forced upon families by governmental and medical and medicare systems.

[See appendix p. 73 for material submitted by Mrs. Yelenik.]

Mrs. YELENIK. In a world where many articulate statements of positions, of beliefs, and of feelings, in a world where much is in disarray and turmoil, and where many clamor to be heard, I would like to speak out for the few who cannot speak out, who cannot yell out their wishes, who if they speak at all speak to us in gentle whispers. I would like to tell you of the whispered desires of one of these many, of my father, Harry Jackson.

My father came to this country in 1921 from Russia, one of many Russian Jewish immigrants; immigrants seeking to live well and work hard in an atmosphere free from persecution. My father worked during the days, and studied at night, Plato, and the scientists and philosophers being his favorites. He became, and remained a master electrician; a man honored and respected by those he worked with and for, and by all who knew him and loved him. He was a man of few words, and of many principles; principles which he upheld all his life.

It was in the 68th year of this rich and loving life that my father began to experience the first symptoms of the illness that was to wreck havoc with his days and nights until his death this past February 5, 7 years later. The name of the illness my father had is Alzheimer's disease. I stress the name because many do not know of this disease at all, and some who do do not even honor its horribleness by naming it. Often Alzheimer's disease is lumped together with words like "senile," or the "confusions of the old," or the "childishness of the old." Alzheimer's disease does not create children out of the old, nor pet-like docile creatures out of human beings. Alzheimer's disease takes usually very physically healthy, mentally sound and productive full-living adults, and slowly and relentlessly by the slow and steady destruction of brain tissue which first attacks the memory and later destroys abilities to perform from the most complicated to the simplest tasks, makes its victims finally totally dependent for their care and well being on others. Alzheimer's disease robs those who suffer from it of their special skills and unique talents. It does not, however, rob people of their dignity, nor of their love for life, nor of their love for their families, and their known surroundings, and cultural and ethnic backgrounds. It does not even rob them, as in the case of my father, of their love of the beauty of fine music, or of their sense of humor, or of their joy in living. Alzheimer's disease does not rob them of these things that make life bearable and still pleasurable. Society does.

Through inadequate medical, medicare, and social services, through the lack of adequate and well proportioned homemaker care services, especially in the evenings and nights when such care is most needed and most lacking, through a system that encourages and sometimes forces families at every step of the way to isolate and alienate the victims of Alzheimer's disease from good and loving homes and family care to institutional care, through these things society adds to the anguish of those suffering from Alzheimer's disease, and to the anguish and frustration of their families. Through these things society robs them.

Alzheimer's disease cries out to be dealt with, to be researched, to have programs funded which begin to find medical answers as to its cause, history, and treatment. Organizations are forming, and they need the support of government programs and medical know-how. The way to dignify Alzheimer's disease is to recognize it, to name it, and to begin to find ways to eradicate it so that the vital and productive people it strikes down can continue to do their work in and for society, and can go on with the business of living. Until the time comes when Alzheimer's disease can be eradicated, or at least made treatable, while it still remains an unknowable, and to a large degree unmanagable disease, until that time what society needs to do, and what I am pleased this committee is at long last addressing, is to help through the augmentation of full day care facilities for the elderly, and through improvement and amendation of medicare services, and through financial support for family care at least equal to that being given to institutions, give older people like my father the ability to remain in their homes with those who love them, and who they love, and who are trying to give them the best possible care.

Those, who in their prime adulthood worked to make our society the best and most just in the world deserve no less than that from the society they called their own.

My father, until his death, remained at home in the excellent and exceptional care and never-ending affection of my mother, Bessie Jackson, and of his family and friends. This kind of care requires 24-hour-a-day attention, and it is as exhausting as it is worthwhile. In this home my father laughed, and ate his meals, and walked around inside, and in the park he enjoyed so much. In this home he smiled, and hugged, and loved us. He wore the clothes he knew; ate the foods he loved; was surrounded by the pictures and furniture he had cherished all his life, and practiced the rituals of family and religion that give quality to life and to the passing of the days. It was in this home that, even during his illness, he loved and watched grow his grandchild, Daniel Adon Yelenik, and was loved and cared for in return by that grandchild; a heritage and a generational link that would not have occurred outside of that home. We won the battle to keep my father where he wanted to be, and remain, because of my mother's dedication, and drive, and love, and against incredible obstacles and blocks placed upon us by present systems.

In all of this time, the strongest and most positive support of the kind we needed and wanted most was given to us by the Support Center of Wheaton, Md., Jim MacRae, director. It was at this center, under the direction and supervision of very able, skilled, and compassionate director, and staff workers and volunteers, that my father, on Tuesdays and Thursdays of each week, from 10 o'clock a.m., until 3 o'clock p.m., was treated in a manner that was an extension of his home. At the center among the staff, and the other elderly clients it services, my father was exposed to a bright and loving environment that tried to stimulate him, and others, on a level appropriate to their abilities. It was at this center that the full range of my father's magnificent personality became known and appreciated, and finally loved. And while it is to the full credit of the center that this happened, it is also far more natural for this to occur through a day care center that is in partnership with the family in caring for an elderly, ill person, than with an institution that is in pseudo-substitution for that family and home.

Day care facilities for the elderly allow the old and sick to keep what is most vital for them during this difficult period: Their roots, their background, the history of their achievements, their likes and dislikes, their place in society; perhaps not the full active place they desire, but nevertheless, a decent, respectable place, not living off and away from the world, but still being in and of the world they still desire to hold on to, and have a right to hold on to, and to be protected and encouraged to hold on to.

At the center my father could be as he was in a pleasant and supportive environment. The people there became an extended family to him and to my mother, for the center provided her also with the things she needed most, some private time free from the anxiety of caring for my father, and most importantly free of the worry that he was being improperly cared for. The center and my mother could share things, good things, and problematic things. Everyone makes mistakes. Times are difficult. The family errs sometimes; so does the center, but the overall commitment is clear to and by the family, to and by the center, to and by the patient.

The center was a pleasant place where my father could go to be with people who cared, and amongst others who, like himself, needed to be cared for. The center was a fine place to be, and the finest thing of all was that he, and everyone there knew that when he left the center, he would come home to us to be with his family where he belonged.

At the services on the day we buried my father I remember my mother crying out only once, and that was when my father's friends from the center came to say a final good-bye to him. The director, and staff, and clients came, another man with that special look of Alzheimer's sufferers.

Nursing home care, institutional care may be the answer for some, may even be the need and desire of some, but for the many who, like my father, abhorred in the days of his health and well being, their concept and philosophy and the all too frequent indifferent or demeaning care they offer, society must support alternative methods of care for the ever growing number of the old and the ill.

I suggest from our own experiences that one of the most loving, productive, constructive, and cost effective—and I emphasize that so powerful last term—alternatives, is by increasing aid to the families who desire to keep their old and ill ones in their home, and by increasing the funding, and expanding the services offered by day care facilities for the elderly. This is the direction and care toward which I believe society must now begin to work in practice. Professional verbal support for home care, and day care must be backed by the practical support of programs and funding.

Thank you.

Mr. **Bonker**. Thank you, Mrs. Yelenik, for providing the committee with such a moving and eloquent statement.

Before you proceed, Dr. Feng, I would like to announce the presence of Congressman David Evans from Indiana, who is a member of the committee. You may proceed.

STATEMENT OF PAUL FENG, PH. D., CLINICAL PSYCHOLOGIST, DANVILLE STATE HOSPITAL, DANVILLE, PA.

Dr. FENG. My name is Paul Feng. I have my Ph. D. in clinical psychology. I have practiced as a clinical psychologist of Danville State Hospital, Danville, Pa., for the past 10 years. I am also a college professor of Psychology and Sociology for Williamsport Community College, Williamsport, Pa.

My mother came to this country in 1923. The reason for her coming over is because of trying to run away from an unpleasant political climate in China. She came here and worked very hard, and my father and her slowly accumulated a small amount of wealth, but unfortunately, there came the depression. Then, they had to start all over again. My father died untimely when he was 48. My mother, being a very strong-willed woman, worked hard as an antique dealer and put me through college and I got my Ph. D. from NYU. She worked for many years as an independent and hard-working small business woman. Somehow, just like any other person, she made the wrong decision of investing in stock. Shortly before she turned 65, once again the bad luck struck. She lost all of her lifetime savings, so she got a very minute amount of social security, and 2 years ago she suffered a stroke which paralyzed the right side of her body.

But I have told, as I have mentioned before, my mother was a very strong-willed lady, and she will not give up, nor will I. At first I was thinking about taking her to some places as Mr. Bonker mentioned, the social center for the elderly, or senior citizen elderly center. I went there and observed how they took care of the elderly people, and I was greatly dissatisfied with the way they did it. There, the whole group of those senior citizens, working hard all through their life, were being treated like a pile of garbage. They were not being taken care of at all. In fact, my mother told me that when the time came for going to the toilet, she requested somebody to wheelchair her to the toilet, and not one person responded. I do not want to mention specifically what organization it was, but that happens to be one of the better senior citizen's center, after my careful investigation, that I sent her to.

I also thought about taking her to some so-called church-related organization. As impressive as they sound, the nurse at one of the leading church organizations in the Rockville area where we used to live, told me:

> We cannot take care of those citizens who cannot take care of themselves. If they are partially incompetent in handling themselves, those are the people we cannot care. We only take care of those people who can take care of themselves.

I want to pinpoint the difference between the so-called Senior Citizen Center, and a special skilled center, such as the Support Center in Wheaton, Md. I was extremely impressed with Mr. MacRae's competence in running the program. After all, since I did work at a State hospital for 10 years for the geriatrics, I ought to know the difference.

I looked at those people over at the support center, they were being treated like individuals, respected like people, first-class citizens. Why is it those people, after years of work, should be treated just like trash. When things grow old we respect them as antiques, but when human beings grow old they were treated just like refuse. This is really a very terrible and disturbing element of this society.

I am the kind of person that I would go to the center during the regular intervals. I noticed that there were different kinds of programs which are really motivating to those semiparalytic patients. Examples are skilled personnel training those people how to do handicraft work; and another thing is they also have physical therapy. I noticed there was one worker diligently helped my mother to hold on to the rail and walk, and back and forth many times. This is the beginning of the second year, and I notice my mother is improving, thanks to the good care of the support center.

If I would send her to some places, like one of those poorly staffed places mentioned previously and just leave her there and let her be, and slowly she would deteriorate and die. Certainly it would be a pity for a person who would like to really self-actualize herself. There must be a lot of people in the support center that would like to articulate the viewpoint which I have just mentioned a short while ago. I think it is really a blessing for my mother who worked hard for her life, and now, that she was fortunate enough to go to a place like support center in Maryland. This is really an inevitable asset, not only to the senior citizens of Maryland, but also to the working citizens, the relatives of the senior citizens, as well.

I would lastly point out also a very important factor. That is, aside from the physical therapy, and also the occupational therapy the center provides, the center also provides very carefully selected nutritious meals for the senior citizens. My mother goes there two times a week, Wednesday and Friday. When I go there at 3 o'clock to take her out I would ask her what she has done. I also went to the center, talked to the workers, and discussed various kinds of programs. Sometimes we even work together to promote different type of social programs which were basically selling the crafts done by the senior citizens from the center.

All in all, what I am saying is that the whole organization, the support center, is really something to be commendable. This is one thing that the Federal funding was properly spent for the benefit of the citizens.

Thank you.

Mr. BONKER. I want to thank you, Dr. Feng, for taking time to be here to give this committee the benefit of the personal experience that you and your mother have had with this program. It certainly is helpful for those of us on the committee to have a glimpse of these personal experiences as we take up the subject of adult care centers.

Our third, and final witness on this panel is Mr. Horace Woods. It is a pleasure to have you with us this morning, Mr. Woods.

STATEMENT OF HORACE E. WOODS

Mr. WOODS. Thank you very much.

What follows is my testimony in support of the continued need for senior day care centers throughout the country. Because they filled a void in my life, I have the fondest regard for the Woods Adult Day Care Center. Three years ago, while recuperating from a stroke, the Health Department therapist suggested that I attend an adult day care center for continued maintenance therapy, both physical and mental. Thank God, in November 1976, I was accepted by the Woods Adult Day Care Center in Severna Park, Md. At that time despondency, and a feeling of uselessness prevailed in my life.

Usually, in the case of senior illness or handicap, he or she experiences a traumatic shock when they discover their inability to function as well as before. Prior to my stroke I worked with retarded adults in work training at the Providence Center in Annapolis, Md., for 5 gratifying years. Married, I lived with my wife in my own home. On acceptance at the day care center, consideration of my physical limitations were dealt with, being paralyzed on my left side. The therapist from the health department followed me at the center during this transition time, and provided a physical fitness program for the center staff to continue during my maintenance routine.

Also, I participate in the center's activities learning to make tapestries by using a punch needle with one hand, and later teaching others how to perform also with one hand. An aide encouraged me in creative writing, and much to my surprise I found myself developing my latent talent of writing. These associations renewed my usefulness, my sense of purpose, and my hope for the future. I regained my confidence in my ability to assist and train. It was quite a relief to get out of the house for a few hours daily to meet new friends, and socialize with my peers.

While my attendance at the center was without a fee, my home was at a great distance and I had to pay for my own transportation. Unfortunately, it was so expensive I could only afford to attend 2 days a week.

The counseling and training at the center taught me to live more independently by strengthening my family ties, as President Carter has advocated, and to remain in my community, dispelling my fears of institutionalization. At the same time, my presence at the center allowed my family to fulfill their daily obligations content in the knowledge that their loved one was adequately being cared for during the day.

Now a widower, I graduated from the day care center, and now attend a senior center closer to my home. While transportation remains a problem, I have been able to maintain my own home and use the meals on wheels service. Physical, mental, and social rehabilitation, the prerequisites for a full life in our waning years, is available at the day care center through their counseling activities and associations. Again I have a feeling of self-worth. I have a new lease on life. Adult day care centers are a godsend.

During my 3 years at the center I witnessed some dramatic changes in certain participants. Those who had withdrawn into a shell became actively involved in activities and relationships, and those who had been rejected looked forward to the center as a haven, a home away from home, all due to the atmosphere and the knowledge that someone cared.

With a waiting list backlog, the need for day care expansion is there. What is needed now is for all society to care.

Thank you very much.

Mr. **Bonker**. Thank you, Mr. Woods, for being with us today. Once again, I think you have given the committee the benefit of a personal experience which is so important to our understanding of these programs.

At this time I would like to call on Congressman Ratchford for any questions he may have.

Mr. **Ratchford**. I do not have any questions, Mr. Chairman, just a comment that this type of testimony is graphic evidence of the fact that what we need in the area of aging is a continuum of care. Connecticut, by no way, has completed its program, but its program includes home care. Its program is beginning to include day care. Its program also includes nursing home care, and I think as testimony develops we will see that if there is correct assessment in monitoring, that in many, many cases for the individual who needs the type care that has been described this morning, that care can be provided in a day care setting so that the individual can go there, be reviewed, receive the type medical treatment necessary, and still go home in the evening. And this, to me, is certainly much more humane, and is proving in Connecticut to be more economical than to say to that person, "The only option you have is because you're too sick to stay at home and receive care, is to go into a nursing home." And each instance that I have to encourage this type of care, whether it is through changes in the medicaid law, the medicare law, or title XX, wherever given the opportunity I will vote to expand the law to include this type of coverage.

Mr. **Evans**. I have no questions, Mr. Chairman.

Mr. **Bonker**. OK. I want to once again thank each of the witnesses, and also to commend the committee staff for scheduling people who have personal experiences. Too often we hear from the professionals first and schedule the people who have the experiences later. I think this is a proper setting for us to proceed with these hearings. Thank you again.

We would now like to make a slight modification in the program, and call up the third panel, which includes Dr. William Weissert, Anne Klapfish, and Charles E. Reed.

Dr. William Weissert is the senior research manager of the National Center for Health Services Research, Office of the Assistant Secretary for Health Research, Statistics, and Technology, Department of HHS, though I am informed by staff that your statement today is not necessarily the official position of the administration.

I might also mention that Dr. Weissert and I served as fellow staff assistants in the Congress 16 or 17 years ago, and we are still around, and still specializing in the same issues. It is a pleasure to greet you, Dr. Weissert. I understand your study is somewhat controversial, so we are very interested in what you have to say this morning.

STATEMENT OF DR. WILLIAM G. WEISSERT, SENIOR RESEARCH MANAGER, NATIONAL CENTER FOR HEALTH SERVICES RESEARCH, OFFICE OF HEALTH RESEARCH, STATISTICS, AND TECHNOLOGY, OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. **Weissert**. Thank you, Mr. Chairman.

You are correct that I appear as a researcher here, and not as a policy spokesman for the Department.

Thank you for inviting me. I appreciate the opportunity to tell you about the findings from a study that we recently completed on the costs and effects of adult day care.

The study was conducted by the National Center for Health Services Research, which is part of HHS, in response to a congressional mandate contained in section 222 of Public Law 92-603, which were the 1972 amendments to the Social Security Act. The purpose of this study was to determine whether or not day care services would improve patient outcomes or would reduce costs. It began in 1974 and ended in 1977, and the data were analyzed in 1978 and in 1979.

Services were provided by four day care programs which were reimbursed through medicare waivers granted under the special authority of section 222. The programs operated in Syracuse and White Plains——

Mr. **Bonker**. May I interrupt just for one moment, Dr. Weissert? You said that the services were reimbursed through medicare?

Dr. **Weissert**. That is correct.

Mr. **Bonker**. Is this money that would have otherwise gone to medicare patients, or is this an administrative category from which this money was drawn?

Dr. **Weissert**. The dollars came from the trust fund. They were health care dollars. The section 222 authority allows the Secretary to expand services beyond what is now covered by legislation and regulation, and that was the case in this study.

Mr. **Bonker**. So instead of the money going directly to medicare recipients, or patients, or to providers, it went to support the Center and its services?

Dr. **Weissert**. That is correct.

Mr. **Bonker**. OK.

Dr. **Weissert**. The patients served were medicare eligibles.

As I said, the programs were operated in Syracuse and White Plains, N.Y.; Lexington, Ky.; and San Francisco, Calif.

The programs studied were what has been called the health-oriented type of day care, rather than the social type of day care which has become much more prevalent in the United States. "Health oriented" meant that patients received nursing supervision, meals, transportation, social work services, and health services such as physical therapy, occupational therapy, or speech therapy and other related services as they needed them.

Six hundred forty-four patients participated in the day care study. They were all medicare eligible. Their average age was about 74, and about half of the patients were 75 years old or older. The majority was female. Eighty percent were white. Three-fourths lived with family or others. More than half were severely dependent in the activities of daily living. Almost a third were only minimally dependent. Three-fourths came from the community rather than from a hospital, which means that one-fourth came from a hospital, and circulatory disorders and injuries due to fractures were the most prevalent diagnosed conditions suffered by the patients.

Patients were referred to the study; that is, to the day care programs and the research, by their physicians, by hospitals, community service agencies, by welfare departments, and by the families of patients. Of course, only those who wanted day care were studied, since it would not be possible or worthwhile to provide day care to patients who did not want it.

All patients were assessed by day care staff teams which included physicians, nurses, social workers, and sometimes one or more therapists. If the team felt the patient might benefit from day care, the patient either was enrolled in day care, or was assigned to a control group which did not get day care, but was used for comparison purposes with the patients who did get it. Each quarter, the two groups' health and social status, mortality and use of health services, was compared.

Results showed that day care patients did no better than control group patients on most measures, including physical functioning, mental functioning, contentment, activity level, or hospitalization. Those in the day care group did have a lower rate of nursing home use and lower death rates, but when more sophisticated statistical techniques were used, it became evident that these benefits were almost totally due to small initial differences in diagnosis, age, sex, living arrangements, race, and dependency level between the day care and control groups rather than any benefit of day care.

Cost findings were no more encouraging. For the day care group, medicare reimbursements were almost three-fourths more than the control group.

Two other findings are important. First, each day care program had a difficult time getting enough patients. Intake periods had to be extended several times. I would add on that point that in an earlier study of ten day care programs, none of them had a waiting list, and each program had a quite small population.

Second, in this study, the rate of nursing home use was extremely low. Only less than one-fifth of all patients entered a skilled nursing facility. This indicates that most patients who used day care in this study were using it as an add-on to existing services rather than as a substitute for nursing home care.

One important limitation on the applicability of these findings to the whole day care question you are considering should be noted. As I indicated, this was a study of the health oriented type of day care, not social day care. Health oriented day care is more expensive and usually serves sicker and more dependent patients than social programs.

In the study I mentioned which I did in 1974 and 1975, I found that social day care programs were considerably less expensive than the health-oriented day care programs studied here. I concluded then, in a sense as an advocate of day care, that day care might be cheaper than nursing home care, but the critical question was, would it serve the right patients. In other words, unless day care can be shown to reduce use of other expensive services, it will always be more expensive regardless of what it costs. We found in this study that most patients used it not as a substitute for existing services, but as an add-on, and so it cost more. Nor were these extra costs offset by beneficial effects on patients.

In summary, we used a sophisticated research methodology. In most cases we used experienced day care providers. These were providers who had won competitive bids to provide day care in this experiment and at the time represented the state of the art in day care, and we assessed a large number of potential benefits of day care, but we found no significant benefits, while we did find high costs.

Of course, this is one study. As a responsible researcher, I would urge the committee to seek additional research before drawing conclusions.

Finally, this study has been published by the National Center for Health Services Research, and is about to be published by some of the leading scientific journals. In that context, since there is some tendency to be very critical of findings that are, in this sense, counterintuitive, and also very disappointing, I think understandably there has been a considerable amount of criticism of the study.

It is worth noting that a very distinguished research panel advised in this research, and reviewed the research methods and the analysis. The panel included Dr. Sidney Katz as chairman. Dr. Katz is the inventor of the principal scale for measuring functional disability in the elderly, and has been the leading researcher in the field; Dr. Robert Boruch, from Northwestern University, a nationally recognized research methodologist; Dr. David Rabin at Georgetown University, a research physician, and recognized specialist in research on the problems of aging in complicated social experiments; and other distinguished researchers. Copies of these reports are available from my office.

Thank you.

Mr. Bonker. Thank you, Dr. Weissert. I can see why your study is controversial. You say that this is not a substitute for existing services. Therefore, it costs more, while not necessarily providing the benefits. This ought to be a challenge for some refutation by our next two witnesses who are very experienced in this area and have done, I think, commendable work. It is timely now that we hear from Anne Klapfish, who is director of Adult Day Health Services, Massachusetts Department of Public Welfare. We appreciate very much your coming down to testify this morning.

STATEMENT OF ANNE KLAPFISH, DIRECTOR, ADULT DAY HEALTH SERVICES, MASSACHUSETTS DEPARTMENT OF PUBLIC WELFARE

Ms. Klapfish. I am very pleased to be here, as well.

Ironically, as I implore you today for recognition of adult day care as a viable and integral component of the long-term care continuum, 6 years ago it was the Federal Government through the Department of Health, Education and Welfare, that implored Massachusetts and other States to recognize the need for the establishment of alternatives to long-term institutional care. Adult day care was recommended as one such alternative.

Due to Federal prompting and great interest on the part of State policymakers and practitioners, the Massachusetts' Medicaid program in 1975-76 awarded six contracts to nursing homes, hospitals, and community providers to operate adult day care programs in a 1 year pilot study.

Although Federal guidelines and various experts in the field suggested that adult day care was divided into three distinct models of care: a therapeutic/rehab model; a health maintenance model; and a social model, Massachusetts opted for a different route. From a demographic, client need and cost efficiency standpoint, it was felt that a merging of these models would be more appropriate.

In 1977 the six pilot programs were evaluated. This evaluation demonstrated that adult day care was indeed a deterrent to institutional placement, that it was cost efficient, that there was a high degree of client and family satisfaction with the program, in short, that it was a workable and necessary service option in Massachusetts.

The evaluation study resulted in a commitment by the State to expand adult day care services. This commitment went beyond a dollar commitment from the medicaid program. An Interstate Agency Committee was formed to input into major policy decisions, and to, along with Health Systems Agencies and area agencies on aging, review incoming adult day care proposals. In addition, area agencies on aging and several local communities contributed the necessary seed money for day care development.

The net result of all of this is that today in Massachusetts we have 45 approved adult day care programs, and expect by fall to have over 50 programs.

The major components of the Massachusetts Adult Day Health program are: health restoration, monitoring and supervision, social service counseling to clients and caretakers, therapeutic recreation, social interaction, personal care services, nutrition, and transportation services.

The staff of each program, in a ratio of one staff person per every six clients daily, is comprised of full time health professionals, social service professionals, a therapeutic recreation director, aides, and physical occupational and speech therapy consultants. Programs are reviewed quarterly for regulation compliance and quality assurance.

In Massachusetts we are currently serving over 1,800 people ranging—and I think this is important—from age 24 to 99. It is significant that at the point of admission to the program, all clients are deemed by nursing review staff to be both eligible for, and in risk of intermediate or skilled nursing home placement.

It is also significant that the per diem rate for adult day care services is currently $16 per person. In addition to the per diem rate, the Massachusetts Medicaid program pays for transportation and direct therapy costs. The total average cost for adult day care services in Massachusetts—and I will remind you that it is a health oriented, very strongly health-oriented program—is $23 to $24 per person per day.

Mr. BONKER. May I interrupt to ask how that reimbursement fee would compare with your current nursing home Medicare fee?

Ms. **Klapfish**. The average for multi-level nursing home facilities in Massachusetts is approximately $33 per day now, so it is considerably less.

Mr. **Bonker**. Ten dollars a day, but it does not provide overnight, around the clock nursing services, or food?

Ms. **Klapfish**. It provides a hot meal daily, plus two snacks.

Mr. **Bonker**. Is that part of the title VII nutrition program, or is that an extra?

Ms. **Klapfish**. Neither it is part of the title XIX dollar that is being used to reimburse for the day care program.

Mr. **Bonker**. OK.

Ms. **Klapfish**. It is important, I think, on that question to note also that usage of day care in Massachusetts on average is 2.7 days per week per person. Given that the per diem rate of day care is approximately $10 less than multiple facilities, and given that people in nursing homes are there 7 days a week, you begin to see a considerable cost difference.

Mr. **Bonker**. Does that also include transportation costs to and from the facility?

Ms. **Klapfish**. Yes. The $23 to $24 a day includes the average cost for transportation, the average cost of direct therapy services that are needed by the person in the day care program, and the entire range of day care services that I had listed before.

Mr. **Bonker**. One final question on this segment. If there were no adult care facility, would that person go to a nursing home, or would they be in their regular home?

Ms. **Klapfish**. I think that the question of add-on versus substitute service is a difficult one. My best estimate is that at least half of our 1,800 people that are now in day care would, in fact, have gone into a nursing home given the family situations that they were in, given their disabilities, et cetera. All people even though they are eligible for nursing home placement, are not going to go in. Circumstances may keep them out. They may just refuse. However, they were all considered eligible. They all would have been accepted into nursing homes, given that there were a bed available for them, and I think in that sense you can say that it is a substitute in many ways, rather than an add-on service.

Mr. **Bonker**. Yes, but that would also have to be noted in any cost comparison.

Ms. **Klapfish**. Yes, that is true.

This brings us into the Weissert report. It is obvious that the findings in Massachusetts differ greatly from the glaring conclusions drawn in Dr. Weissert's report, those conclusions most notably being that the average cost of a health oriented day care program is $52 per day, and that adult day care is not a substitute for nursing home placement.

These conclusions, although certainly devastating to adult day care through their visibility, are not, however, I do not think, the major sin of the Weissert report. The sin is really—does that bell mean I have to stop?

Mr. **Bonker**. You may proceed. That is intimidating only to those of us who have to vote, and we can go for about 10 minutes.

Ms. **Klapfish**. Does that mean I will lose my audience?

The sin of the Weissert report, I believe, is the thrust of what seems to be only major study in adult day care to be undertaken by the Federal Government. First, the report compares the impact of day care on the cost and usage of skilled nursing home care from a medicare focal point. Experience in Massachusetts indicates that day care clients, percentagewise, are most likely to enter or be at risk of intermediate nursing home care. Intermediate care facilities are largely paid for with the medicaid dollar, not the medicare dollar. To look at the potential cost savings of adult day care in comparison with institutional care from the focal point of the Federal health care dollar, one must examine medicaid costs in relation to day care before conclusions can be drawn.

Second, the selection of programs studied in the Weissert report ensured that the average cost figures for health oriented day care would be higher than representative in other health oriented programs nationwide. These programs were gilded—some of these programs, I should add—were gilded with a range of professional services and staff that is not representative of most of the health oriented day care programs in this country, and therefore result in inevitably higher costs. Also, there was no evidence in terms of the add-on versus substitute issue raised in the report. There was no evidence the clients in either the experimental or controlled group of Dr. Weissert's report, and perhaps he can refute this, were assessed to actually be at risk of institutional placement upon entering the program or the study.

It is unfortunate that the thrust of cost savings and substitute service issues cloud some of the more positive aspects which Dr. Weissert just said were not so positive, but when I read the report that I found. For example the report states, and I quote, that "higher proportions of day care experimental than control group patients improved or maintained in levels of contentment, mental function and social activity." In addition, the report suggests that those in day care experimental groups were kept alive longer through the program.

It is rather sad for me to think that not only the quality of life, but the length of a life also becomes a secondary issue to the dollar. Medicare decided not so long ago that prolonging life was worth $600 to $700 per day for renal dialysis patients. Now, we are sitting here arguing today that $52, which I do not believe is even a correct figure for the norm in this country, is too much to prolong the life for adult day care clients.

In conclusion, I would like to take this opportunity to offer one recommendation to the committee for consideration. I made one recommendation so that would sound short, but it really has several parts. I recommend the establishment of a Federal office on adult day care whose function would be to establish policy standards that would insure a basic nationwide uniformity and understanding of adult day care, yet be flexible enough in these standards to allow for demographic and client need differences; to explore ways of integrating or channelling the multiple funding sources now being used for adult day care, thereby easing for practitioners and clients a major barrier in the development, continuation, and use of adult day care; to insure—and this is very important—equitable funding for the broad range of persons appropriate for day care service to make day care not just a program for the very rich and/or the very poor; to act as a coordinator of, and a clearinghouse for the wide range of existing material in the adult day care field; to provide leadership and technical assistance in the further development of adult day care.

I close with the reminder that day care is an essential and cost efficient program. It deserves your utmost attention, and I hope after carefully weighing the testimony that you hear today you will initiate action to insure that adult day care becomes both an accepted, and an expected integral component of the long term care continuum.

Mr. Bonker. Thank you, Ms. Klapfish.

I think that it would be advisable for us to go to a short recess in order to vote on what may be two issues, and then we will reconvene and pick up with Mr. Reed, and then open for questions. So we will go into recess for no more than fifteen minutes.

[A short recess was taken.]

Mr. Bonker. The subcommittee will come to order, and the witnesses please come before the witness table.

The subcommittee has heard from Dr. Weissert, and Ms. Klapfish, and now we will proceed with our third witness, Charles E. Reed, who is director of the Washington State Bureau of Aging, and I might mention with some local pride that he is one of the finest directors of aging in the country, and has demonstrated his ability in that capacity in the State of Washington, so it is really a pleasure to greet you, Charlie, and I am looking forward to your testimony.

STATEMENT OF CHARLES E. REED, DIRECTOR, WASHINGTON STATE DEPARTMENT OF SOCIAL AND HEALTH SERVICES, BUREAU OF AGING, OLYMPIA, WASH.

Mr. Reed. Thank you Congressman Bonker. I am very pleased to be here today and have the opportunity to talk before you and the other committee members.

As you know, Congressman Bonker, the State of Washington has worked long and hard to develop alternatives for older persons in the continuum of care. We have a day care program in our State that we feel is a very significant alternative. We have been encouraged to develop this program, the very sophisticated, powerful senior constituency in our State that you are well aware of.

In Washington State we call day care day health. There are ten day health centers that are funded through the State Bureau of Aging, and an additional six day health programs funded through fees and donations.

Mr. Bonker. May I ask, the ten day care centers, are they apart from the regular senior centers that we know of?

Mr. Reed. They are apart from the senior centers in our State. That is right.

Mr. Bonker. Do they provide any other services, other than those relating to health care services?

Mr. Reed. Well, most of them are freestanding. There are a few that are in mental health centers in our State, but most are freestanding programs that serve for the purpose of primarily day care.

Mr. **Bonker**. Is this in the health, or in the social category?

Mr. **Reed**. Well, it is a combination of the two, and when I get through my testimony here you will see that it is the health model that Dr. Weissert talks about, there are definitely social services offered there, as well.

Mr. **Bonker**. Thank you.

Mr. **Reed**. The centers in our State do operate five days a week. The average attendance at each center is somewhere between 20 and 30 persons. The stated purpose of the program is to prevent, or delay entrance into 24-hour care, or reduce the length of stay in 24-hour care. The primary target population are those older persons who are mentally, physically, socially, or emotionally impaired and need day health services to maintain or improve their level of functioning so they can remain in, or return to their own homes. A secondary target population is persons who cannot be left unsupervised, are living with relatives, or friends who provide the supervision they need to remain in the community, but need some relief from 24-hour care. Persons living in congregate care, or nursing homes, can receive day health services for a limited period of time when it is reasonable to expect that these services will enable them to move to a lower level of care. The required services that are provided in the day health centers in our State include intake assessment with treatment planning and quarterly evaluations, health monitoring, rehabilitative nursing, occupational therapy, social services, activity therapy, personal care, a noon meal, and transportation. Day center staff arrange for participants to receive physical therapy, and speech and hearing therapy outside the center when these therapies are ordered by the physician.

The day health standards——

Mr. **Bonker**. I am sorry to interrupt. Let me ask you about that. You say that those services can be provided outside the center if recommended by the physician?

Mr. **Reed**. That is correct.

Mr. **Bonker**. If it were a problem, would not the physician just recommend other services, without having to go through the center?

Mr. **Reed**. Well, they could. As part of the treatment plan though, at the center, the person may receive physical therapy, and the day health centers do not have physical therapists on staff, so they arrange for the older person to go to a physical therapist, and that is paid for through the day health program.

The day health standards require that centers maintain a staffing pattern which includes at least a director, a registered nurse, an occupational therapist, social service specialist, activity coordinator, and aides as necessary to have a sufficient staff/patient ratio.

Most of the day health patients have multiple impairments. In our State we administer to each patient the OARS, the Multidimensional Functional Assessment Questionnaire developed by Duke University to determine the level of care needed.

The physical handicaps most common to the day health participants are stroke, arteriosclerosis, heart disease, hypertension, diabetes, arthritis, and severe vision problems. The most common mental handicaps are schizophrenia, paranoia, depression, senile dementia, Alzheimer's Disease and anxiety.

The mean age of clients enrolled is 74, and just about 60 percent of the clients are considered to have incomes below 40 percent of the State median income.

The cost for day health care in our State is $21.91 per day, excluding their transportation. With transportation, which is about $4 a day, it rounds it out to approximately $26 per day. We are in the process of collecting more specific cost information in an effort to get increased title XIX funding, which is now only $21.60 a day in our State. We will forward this cost information to this Committee when we get that, which will be in the next month or so.

Mr. **Bonker**. What is the per day reimbursement rate for nursing home care under medicare, Mr. Reed?

Mr. **Reed**. It is $33 a day in the State of Washington.

Mr. **Bonker**. So the cost ratio is about the same as that which was referred to by Ms. Klapfish.

Mr. **Reed**. That is correct.

We have three major sources of funding for day health care in the State of Washington. The first, and major source is the State Senior Citizens Services Act, which is unique to the State of Washington, which provides almost half the funding for the day health programs. We also have title XX funds, and title XIX funds. Lack of funding and rigidity of the medicaid regulations are the most significant barrier to further development of adult day health in our State. We get the same amount of title XX funding we received 3 years ago, as Washington State is always at the title XX lid. Due to inflation, fewer title XX clients can be served each year. We are unable to divert more State funds to day health for the same basic reason. Funding has not kept pace with inflation, and we have all we can do to fund the same number of clients each year. The State money will not stretch to serve additional clients. Our ability to use medicaid is limited because the State medicaid agency requires us to use State money appropriated or for aging services to cover the State match. For all other medicaid programs in the State of Washington, the State match is supplied through the medicaid budget, and we are currently negotiating with the title XIX people in our State to change that situation.

Mr. **Bonker**. Recently the State of Washington enacted legislation which expanded senior citizen programs, and added considerably to the funding of those programs. Are there any State funds from this source that you use?

Mr. **Reed**. Yes. That is the State Senior Citizens Service Act, and about half the funds for the day health program comes from that source, that State source, but that source, while it seems like a lot, and it is a lot, is still limited and is used for a number of different services in the continuum of care. We have not received a major increase in the last 2 years. We are operating at current level.

Mr. **Bonker**. Washigton State's commitment is unique in that sense. Not many States have made a similar financial commitment to senior citizen programs. If the State funding were wiped out, or if there are other States that do not have a source of funding, would it be possible to continue that same level of service?

Mr. **Reed**. It would not in our State. It would do away with half the program at the very least, but it would do away probably with three-fourths of it because the State appropriated aging dollars are used to match the title XIX dollars, so we would do away with all the State funding, and also the title XIX funding at this point in time if the State dollars were not there.

In addition, it is very time-consuming for day centers in our State to meet the medicaid regulations in regard to physician orders for services. Day health was originally classified as a clinic service in our State, and the client's physician had to order the service before the client could be enrolled. This was approved by the central staff here in Washington, D.C. After that approval was given a change was made, and it was decided that a physician had to be on site, had to be employed by the day health program to be considered a clinic service. This requirement would substantially add to the cost of day health in our State, and we also thought it would be very inappropriate. Our goal is to strengthen the relationship between the client and his or her physician, not to weaken the relationship by having the client deal with another physician while at the day center.

To resolve this situation, we have changed the classification for medicaid purposes of the day health centers from clinic to rehabilitative service. Medicare regulations do not require that a physician be onsite for rehabilitative services, but now the client's physician has to reorder the service every 3 months. Physicians find this somewhat ridiculous, considering that the client's mean age is 74 years, and it is unlikely that clients in this age group will be rehabilitated in 3 months. Day center staff spend a large amount of time calling physicians to remind them to send back a signed order so a client will not have to be terminated. For some reason, medicaid requirements for day health in our State require much more physician involvement than do medicaid requirements for home health services and nursing home care.

In summary, I would like to say that in the State of Washington, that the State Council on Aging, which has had a great influence on the development of day health, and most all of the area agencies have documented the need for such a service, all of our day centers are serving as many people as they have funding to serve, and most also have private paying clients. The day centers are unable to accept any new enrollees unless they have a termination, since all possible funding sources have been exhausted. It is clear that day health must have a stable source of funding if it is to grow to where it can serve all of the at-risk people it should be serving. In fact, the program may not even survive if the funding situation does not improve. It is essential that day health be covered under medicare and medicaid, and that both medicare and medicaid regulations have sufficient flexibility to make it practical to use these funding sources for people still living in the community.

The experience in Washington State is that the health oriented day care described by Dr. Weissert does exist. It costs around $26 a day, and is a very significant part of the continuum of care for older persons. It is an alternative to premature and inappropriate institutionalization.

[The prepared statement of Mr. Reed follows:]

PREPARED STATEMENT OF CHARLES E. REED, DIRECTOR, WASHINGTON STATE DEPARTMENT OF SOCIAL AND HEALTH SERVICES, BUREAU OF AGING, OLYMPIA, WASH.

Adult day care, often referred to as geriatric day care, was first developed in Europe in the 1940's and is now an established part of the British and European health care systems. The first similar program in the United States began in 1947 under the auspices of the Menninger Clinic and, while there has been significant growth in the number of adult day care programs in this country, the concept has not yet become a fully integrated component of the continuum of care. However, legislators and the public-at-large are becoming more and more committed to preventing inappropriate institutionalization, and adult day care is a key program in the effort to maintain people in their own homes as long as possible.

Since day care for adults is a relatively new phenomenon, no one program model has been commonly accepted as the ideal. Just the fact that there is little agreement on what to call the program gives some indication of the differences in philosophy about who the target population should be and what services should be provided. Geriatric day care, therapeutic day care, day hospital care, day treatment and day health are some of the terms that have been used to describe a day program for adults that is designed to prevent, delay, or reduce the length of stay in a nursing home or institution. There has been an attempt on the part of various people to define each of these terms according to the type of individuals served and whether health services or social services are given primary emphasis. These efforts have been tremendously helpful in conceptualizing the core services of a day program and most programs, no matter what they are called, do provide socialization, assistance with activities of daily living, a noon meal, transportation and some degree of health and social services. Each state that develops a day care program must decide what, if any, additional services will be offered, how the program will be structured, the level of training that will be required of staff, the relative priority of health services and social services, and whether the program will be oriented toward rehabilitation or maintenance or both. Washington State has made these decisions and has formulated program standards a day center must meet in order to obtain state funding. A copy of these standards is attached.

Washington State opted to call its program "day health" and now has a total of ten day health centers which receive state funding and about six private centers funded through fees and donations. Since we do not have a licensing law for day health, we do not have much information on the private centers. Demographic and program data for the ten state-funded centers is attached.

Our day health centers serve participants for five hours a day, usually 10 a.m. to 5 p.m. Five centers have an average daily attendance of 15-19, three centers have an average daily attendance of 20-29 and two centers have an average daily attendance of 30-39. The stated purpose of the program is to prevent or delay entrance into 24-hour care or reduce the length of stay in 24-hour care. The primary target population is persons who are mentally, physically, socially and/or emotionally impaired and need day health services to maintain or improve their level of functioning so they can remain in, or return to, their own homes. A secondary target population is persons who cannot be left unsupervised and are living with relatives or friends who provide the supervision they need to remain in the community but need some relief from 24-hour care. Persons living in congregate care or a nursing home can recieve day health services for a limited period when it is reasonable to expect that these services will enable them to move to a lower level of care.

Required services that are provided at the day center to all participants as needed are: Intake assesssment, treatment planning and quarterly evaluations; health monitoring; rehabilitative nursing; occupational therapy; social services; activity therapy; personal care; noon meal; and transportation.

Day center staff arrange for participants to recieve physical therapy and speech and hearing therapy outside of the center when these therapies are ordered by a physician.

The day health standards require that centers maintain a staffing pattern which includes at least a director, registered nurse, occupational therapist, social service specialist, activity coordinator and aides as necessary to have a sufficient staff/participant ratio.

Most day health participants have multiple impairmants. The Multidimensional Funtional Assessment Questionnaire (OARS), developed by the Duke University Center for the Study of Aging and Human Development and modified by the Bureau of Aging, is administered to each participant within five days after intake. The purpose of the OARS questionnaire is to assess the participant's level of functioning in five major areas: social resources, economic resources, mental health, physical health and ability to perform activities of daily living. A score of 1-3 in a given area means the participant is not impaired in that area or is only mildly impaired. A score of 4-6 in a given area means the participant is moderately, severly or totally impaired in that area.

Based on 1979 calendar year data, below is the percent of participants who received a score of 4-6 in each of the functioning levels measured by the OARS. The percents do not add up to 100 percent as most all participants are impaired in two or more functional areas.

	Percentage
Social resources	40
Economic resources	29
Mental health	54
Physical health	56
Activities of daily living	54

The physical handicaps most common to day health participants are stroke, arteriosclerosis, heart disease, hypertension, diabetes, arthritis and severe vision problems. The most common mental handicaps are schizophrenia, paranoia, depression, senile dementia, Alzheimer's Disease and anxiety.

The attached data gives detailed information about the characteristics of day health clients, but it is particularly interesting to note the following. Mean age of clients at enrollment is 74 years; 67 percent of clients are age 70 or over; 59 percent of clients are under 40 percent of state median income; 35 percent of clients live alone.

We do not have complete information on the cost per day of day health services as the Bureau of Aging does not directly administer the day health program. Rather, we allocate the Title XX funds designated for day health and state Senior Citizens Service Act (SCSA) funds to Area Agencies on Aging and they in turn contract with the day health centers. Area Agencies are responsible for reviewing center budgets and cost reports and establishing the daily rate, which varies from center to center. The statewide average amount paid by Area Agencies for a day of day health services is $21.91, excluding transportation. This amount does not necessarily represent the total cost of providing a day of service, but it is very close as most day centers include all program costs in their budgets. We estimate it costs another $4.00 a day to transport a client to and from the day center, which brings the total cost to about $26.00 a day. We are in the process of collecting more specific cost information in an effort to get an increase in the Title XIX rate, which is now $21.60 a day including transportation. We will forward this cost information to you when it is compiled. Title XIX pays a flat rate to all day health centers and this rate has not been raised to keep up with inflation. We are now in the position where Title XX and SCSA are subsidizing Title XIX and hope we are successful in raising the Title XIX rate to where it is comparble to the Title XX/SCSA rate.

Title XX, Title XIX and the State Senior Citizens Services Act (SCSA) are the primary day health funding sources in Washington State. An individual day center can qualify for all three sources of funding; we do not have separate Title XIX centers and Title XX centers. We already had a well-established day health program and a set of comprehensive standards when we applied for Title XIX funding. We were eager to get Title XIX funds so we could expand services, but we also decided we would not utilize Title XIX if required to develop separate programs for Title XX/SCSA clients and Medicaid clients. Our day health program provided a complete set of services and afforded each client the opportunity to use both medical and social services to the degree necessary for his or her particular situation. The Bureau of Aging believed, and still believes, that it is administratively wasteful and a disservice to clients to establish one day health program for clients who are physically impaired, another for clients who are socially isolated or confused, and possibly a third for clients who are emotionally or psychiatrically disturbed. Our experience is that client needs cannot be so neatly divorced from one another and that even the needs of a particular client vary over a period of time. An individual with serious physical disabilities or illness will almost certainly have some social isolation and very possibly some degree of depression; the confused or emotionally disturbed client also has a need for health monitoring and nutrition services. People with different sets of problems can help each other improve, and we have found this mutual support to be one of the main benefits of having a day health program that serves more than one target population. We felt it was essential that we stay with the concept of having one day health program supported by various sources of funding, and we were successful in implementing this concept.

The table below represents a breakdown of day health funding for the current year. As the table indicates, the state Senior Citizens Services Act is the major funding source.

Senior Citizens Services Act (SCSA)	$517,485
Title XX	162,462
Day treatment	8,721
Title XIX	152,019
Client match for SCSA	98,280
Private pay	43,752
Total	982,719

Lack of funding and rigidity of Medicaid regulations are the most significant barriers to further development of adult day health in our state. We get the same amount of Title XX funding we received three years ago as Washington State always exceeds its Title XX lid. Due to inflation, fewer Title XX clients can be served each year. We are unable to divert more state funds to day health for the same basic reason; funding has not kept pace with inflation and we have all we can do to fund the same number of clients each year. The state money will not stretch to serve additional clients. Our ability to use Medicaid is limited because the state Medicaid agency requires us to use state money appropriated for aging services to cover the state match. For all other Medicaid programs, the state match is supplied through the Medicaid budget. The Bureau of Aging is working to change this process.

In addition, it is very time-consuming for day center staff to meet Medicaid regulations in regard to physician's orders for the service. Day health was originally classified as a "clinic service" and the client's physician had to order the service before the client could be enrolled in a day center. Day center staff sent the physician a copy of the client's treatment plan at intake and copies of quarterly reviews of client progress. The physician was invited to add his or her input, but did not have to formally reorder the service once it had been initiated. This process was originally approved by Medicaid staff in Washington, D.C., but staff there later reversed the decision and stated that day health centers had to have an on-site physician to qualify as a "clinic service." This requirement would substantially add to the cost of adult day health and we also thought it would be inappropriate. Our goal is to strengthen the relationship between the client and his or her own physician, not to weaken the relationship by having the client deal with another physician while at the day center.

The above issue was resolved by changing day health from a "clinic service" to a "rehabilitative service." Medicaid regulations do not require an on-site physician for a "rehabilitative service", but now the client's physician has to reorder the service every three months. Physicians find this somewhat ridiculous, considering that the client's mean age is 74 years and it is unlikely that clients in this age group will be "rehabilitated" in three months. Day center staff spend an inordinate amount of time calling physicians to remind them to send back a signed order so a client will not have to be terminated. For some reason, Medicaid requirements for day health require much more physician involvement than to Medicaid requirements for home health services and nursing home care.

In summary, we believe Washington State has a quality day health program which does help very impaired people avoid or delay moving into 24-hour care. Day health is included in the State's Title XX and Title XIX Plans and in the State Health Plan. The State Council on Aging and most all Area Agencies on Aging have documented the need for such a service. All of our day centers are serving as many people as they have funding to serve and most also have a few private paying clients. The day centers are unable to accept any new enrollments unless they have a termination, since all possible funding sources have been exhausted. It is clear that day health must have a stable source of funding if it is to grow to where it can serve all the at-risk people it should be serving. In fact, the program may not even survive if the funding situation does not improve. It is essential that day health be covered under Medicare and Medicaid and that both Medicare and Medicaid regulations have sufficient flexibility to make it practical to use these funding sources for people still living in the community.

WASHINGTON STATE DAY HEALTH PROGRAM STATISTICS—CALENDAR YEAR 1979

Data item	Number	Percent
Persons served:		
Male	368	37
Female	628	63
Total	996	
Age at enrollment (mean age at enrollment is 73.5):		
Under 60	54	6
60 to 64	129	13
65 to 69	138	14
70 to 74	192	19
75 to 79	182	18
80 and over	301	30
Income level:		
At or below 40 percent State median income	593	59
Between 41 percent and 80 percent median income	327	33
Over 80 percent State median income	76	8
Funding source:		
Senior Citizen Services Act (State funds)	522	52
Title XX	189	19
Medical, excluding day treatment	179	18
Day treatment	17	2
Private pay	69	7
Other (insurance, charitable donations, et cetera)	20	2
Living arrangement:		
Alone	353	35
With spouse	254	25
With child	166	17
With other relative	42	4
With nonrelative	23	2
Retirement home	6	1
Adult family home	36	4
Boarding home/congregate care	67	7
Nursing home	31	3
Psychiatric hospital	12	1
Other	6	1
Referral source:		
Aging network programs	122	12
Department of Social and Health Services	62	6
Hospital (medical or mental)	75	8
Community Health Agency	176	18
Community Mental Health Agency	99	10
Religious agency	6	1
Private practitioner	37	4
Adult family home/congregate care facility/nursing home	53	5
Relative/friend	274	27
Self	49	5
Other	43	4
Reason for termination:		
Graduation	51	11
Moved out of area	45	9
Too ill/disabled to attend	50	10
Entered adult family home	2	1
Entered congregate care facility	58	12
Entered nursing home	25	5
Entered medical hospital	4	1
Entered mental hospital	24	5
Program not appropriate	126	26
Client/family choice	70	14
Died	26	5
Other	4	1
Total terminations	485	

Average number of days of service provided to terminated clients: Mean—104; Median—22.
Average number of months of service provided to terminated clients: Mean—10; Median—6.
Cost of services provided during 1979—$1,143,480.
Number of days of service provided during 1979—52,180.
Cost per day of service, excluding transportation—$21.91.
Number of clients served during 1979—996.
Cost per client served—$1,148.07.

Mr. Bonker. Thank you, Mr. Reed.

I think the committee now has the benefit of both sides of the issue through Dr. Weissert and his study, and also through the excellent testimony of Ms. Klapfish and Mr. Reed.

Mr. Ratchford.

Mr. Ratchford. Dr. Weissert, perhaps you stated, but I did not hear, what was the date of your study?

Dr. Weissert. There were two studies. One was a descriptive study of day care centers that was done in 1974 and 1975. The controlled experiment began in 1974, and ended in 1977, and then the data were analyzed in 1978 and 1979.

Mr. Ratchford. And how many facilities did you study?

Dr. Weissert. Four.

Mr. Ratchford. Do you think that this is an adequte sample to draw the conclusions that you have drawn as it relates to day care centers?

Dr. Weissert. The conclusions I have drawn are limited to those four centers, and certainly it is adequate for that.

The question I believe you are asking is, should we draw conclusions about other centers from those four, and the answer of course, is no. On the other hand, should you ignore these findings when thinking about this issue, I think the answer to that is also no.

Mr. Ratchford. I think my concern is with the position that you hold, that the study then takes on more significance nationally, and takes on a significance that would suggest that this is the position of the Department of Health and Human Services.

Dr. Weissert. No, I would deny that. It certainly is not the position of the Department. Speaking personally, for myself, my impression is that the Department appropriately does not yet have a position on day care because we do not know the answers.

When you suggest that because I am in HEW that this study takes on more prominence than it deserves, I think you must keep in your mind that research of this type is always very expensive, and is limited to a small number of sites, typically, and we did the best we could to make the most of our investment. That is, we used the most rigorous methodology known to social science; that is, the controlled experiment. And so while it was small, it was large, for example, in comparison to some drug studies, and other studies of medical treatments that affect life.

Mr. Ratchford. But small in relationship to the fact that there are now over 600 day care programs in the United States.

Dr. Weissert. That is true.

Mr. Ratchford. I would be interested in your feelings as to standards, as to whether or not standards should be developed for such facilities. Did you find standards in the four institutions that you studied?

Dr. WEISSERT. Well, for purposes of this study, the people at what is now the Health Care Financing Administration, designed standards that required certain services; the standards that would relate to things that are typical in nursing homes, utilization review of facility, fire regulations, and things like that did not exist for the most part, for day care either in general, or in these facilities.

And along that line I would add that in the earlier descriptive study of 10 centers, we found some instances where I think most health care professionals would have wanted to see standards imposed and met. That is, facilities were not comparable to what we would consider adequate facilities. So I would say if we are going to have day care, yes, we should have standards. Whether they should be National, State, or local standards, I am not prepared to say.

Mr. RATCHFORD. Would you say that assessment in monitoring is a key to what population day care centers should serve?

Dr. WEISSERT. Yes, that is definitely true. I think if—and let me say once more that I am speaking as a researcher, and not for the Department—if I were to make one recommendation as to where we go from here, it would be to say let us try to narrow the population that we are offering the service to so that we increase the potential for having a beneficial impact either on patient outcomes, or on costs.

Mr. RATCHFORD. Some States are designing their programs to serve just those who are in risk of institutionalization. Would you comment on that?

Dr. WEISSERT. I think that is an excellent idea. It is very close to impossible, unfortunately. We find that—well, other researchers have found, for example, if you take a survey of the community you find that for every patient who looks like a nursing home patient and is in a nursing home, there are four or five more in the community with the same characteristics living at home, and we cannot explain why.

By the same token, if you take a community study and list all the characteristics of patients in nursing homes, and outside nursing homes, you find that you are able to explain very little of the difference between who gets into a nursing home and who does not get into a nursing home.

I think that trying to limit the population to those at risk of institutionalization is laudable. I would go somewhat further and require that patients exhibit at least moderate dependency on the Katz ADL scale, and I would, unless there were compelling reasons to do otherwise, I would favor patients coming from hospitalizations, or skilled nursing facilities since we found that those tended to be the patients who had the greatest potential for benefiting.

Mr. RATCHFORD. Well, some States have home health care, day care facilities, nursing home facilities in hospitals. Is this not an appropriate continuum of care, provided adequate standards are set?

Dr. WEISSERT. I certainly favor a continuum of care. If I had been designing the entire concept I would have studied, instead of day care, I would have studied a broad range of services, of which day care would be one, so that there was no chance that I was putting a patient into day care as inappropriately as he might otherwise go into a different service.

But to address specifically the issue of day care, do I favor having it in the continuum, I have to say that it is expensive. Our study indicated that with qualified providers and patients who showed a potential to benefit, it had no significant effects. I have to ask the question, what else are we giving up when we buy day care? Are we giving up, for example, tax credits, or deductions that might encourage the family to do more? Are we giving up congregate housing, for example, which we have very little experience with but seems to be a promising alternative.

Mr. **Ratchford**. But are not those decisions that elected officials have to make?

Dr. **Weissert**. They certainly are the burden of elected officials to make those difficult decisions. What I hope our research can do is—Chester Barnhardt, who studied the functions of the executive used to say, "The principal function of the executive is to make a decision when he does not have any basis on which to make it." We try to contribute to that basis of decision with research.

Mr. **Ratchford**. We have heard the director from Massachusetts, and the director from Washington cite figures that were substantially lower than your survey. Would you comment on that?

Dr. **Weissert**. There are, I think, two comments. One is that we studied four programs, and the range of cost was considerable.

Mr. **Ratchford**. Were they all in the same State?

Dr. **Weissert**. No. Two were in New York. One was in California, and another was in Lexington, Ky.

We found a considerable range of costs. The cheapest one was in Lexington, and was less than $19 a day. There are a couple of things we found. One is that how much a program costs per day is in part a function of how often the patient uses it, so that there was an inverse relationship between daily cost and utilization. The cheapest program had among the highest utilization rates, and the most expensive program had the lowest utilization rates. That reduces the cost difference when you look at them annually.

The other point that I think is important is one that Mrs. Klapfish made. She said, I think, that a desirable kind of comparison is one between the cost of day care on a per day basis, and the cost of nursing home care per day. I did that in an article I published in 1978, and concluded that, gee, it looks cheaper. But the big question that remains is are we talking about the same population; and the answer we found is no, it is not the same population. Only about a fifth of those who participated in the day care program were people who went to nursing homes. The comparison between the cost of nursing home care and day care is really quite irrelevant unless you can prove that you are dealing with the same patients.

Mr. **Ratchford**. Well, are you then rejecting the possibility that the day care facility kept people out of nursing homes?

Dr. **Weissert**. It did not do that in this study at a statistically significant level. That is, when we looked at all of the characteristics that made the control group different than the experimental group in their use of nursing homes, day care was not a significant factor.

Mr. **Ratchford**. What elements entered into your determination that it was not a significant factor?

Dr. **Weissert**. Well, we had a very comprehensive patient assessment that took up to 1 hour and 45 minutes, and we found that when you put all of those characteristics into a formula to analyze the effect of various factors on institutionalization, day care ranked among the lowest contributing to entry.

Mr. **Ratchford**. Well, I have no further questions.

Mr. **Bonker**. Thank you, Mr. Ratchford.

This issue poses something of a dilemma for me, as I mentioned earlier, because of the excellent testimony that has come from Ms. Klapfish, and Mr. Reed, and Washington State's successful experience with this program on the one hand, and Dr. Weissert's excellent study, which has posed some provocative questions on the other, and I think it is appropriate for this committee to sort out these things and reach a concensus on whether or not the Federal Government should become more heavily involved in these programs. I think just to keep the perspective we should point out that presently the Federal Government has not acted directly on adult care centers. It has not been the subject of any particular program, and the funding comes from an assortment of Federal sources, State, and local, and private as well, to support the 600 or so programs that are in existence today. And if I get any messge from your testimony, Mr. Reed, it is that the Federal Government should become more involved, at least in funding of adult day care centers.

You say in your testimony that your concern is the rigidity and the limitations of medicaid regulation and funding, and that it is clear that day health must have a stable source of funding if it is to grow to where it can serve all at-risk people. Further, you say that it is essential that day health be covered under medicare and medicaid, and that both medicare and medicaid regulations have sufficient flexibility to meet this need.

Now, what concerns me is that we are making it possible for adult care centers to compete with other programs for the scarce Federal dollar. We have to look at the cost-benefit analysis to see if money that is siphoned off of medicare, or medicaid, and has gone into adult care centers is going to be more cost beneficial to the patient. I really get troubled when I see us starting to tap medicare because, as you know, Mr. Reed, I have long been concerned about health care for senior citizens, and increasingly I find that the Government is not allowing the full financial benefits that are inherent in the medicare program. Many senior citizens who have in-patient care, or even just go in for physician services under part B, find that because of the assignment fees, and other things, that they have to end up paying $10 or $15 on that doctor's bill. I would hate to see us divert money from medicare, and even medicaid, into other programs that do not provide direct benefits, but a center and services that makes that scarce dollar even less significant for the intended beneficiary.

That leads me to pose this question once again to Dr. Weissert, concerning the cost benefit of day care centers, nursing home care, and home health care services. Are we essentially duplicating these services, or is this an add-on, or do these health care centers complement existing programs? The one persistent criticism we hear is that we have too many programs that are not effectively doing the job. If the Federal Government were to get directly involved in supporting adult day care centers, would that compete with the existing programs, and is it going to be cost effective?

Dr. **Weissert**. Of course, when I answer that I am talking only about the day care programs in this study. We have talked about the limitations of generalizing from this to all day care programs. In this study we found that, with respect to nursing home care, day care was not a substitute. It did not reduce use of nursing homes. In that sense, it was an add-on to existing services.

Mr. **Bonker**. The purpose of the program is to provide alternatives for institutionalized care, and in your study it did not represent any reduction in nursing home care. Therefore, it is not providing an alternative.

Dr. **Weissert**. That is correct. It failed in that respect.

There is, however, another purpose of day care, and that is to provide better care than is currently available, or care that is not currently available to some patients, and we certainly hoped that some patients would receive care in day care that they were not getting anywhere else, could not get, or they would get better care. If that had happened, we should have seen differences between the day care group and the control group in outcomes. They should have shown better physical functioning, higher contentment, better social activity levels, better mental functioning abilities, lower mortality rates. None of those was true; not at a statistically significant level.

Mr. **Bonker**. Most people who go to a nursing home under medicare are referred to the medicare as part of the health delivery program inherent under title XVIII, and that means they go directly from the hospital, to a nursing home, and then, if necessary, to home health care service. You say that in your study almost a third were minimally dependent; that three-fourths came from the community rather than a hospital, so only a fourth of the patients covered in your study actually were part of that process of hospital nursing home health care. The others just came in directly from the community, or through physician referral. Is that the case?

Dr. **Weissert**. Partially the case. It is not entirely true that patients enter nursing homes always from hospitals. Some do. Some come directly from the community.

Mr. **Bonker**. Under medicare, I think they all have to come from a hospital.

Dr. **Weissert**. That is right. Under medicare they must come from a hospital. One would hope that day care would prevent—there has been some probably legitimate criticism of that requirement, and that is that if you need a nursing home the route to get there is to go through a hospital, and that may precipitate unnecessary hospitalizations.

In this study we had hoped—and the reason we admitted people directly from the community—we had hoped that we would prevent unnecessary hospitalizations, as well as unnecessary nursing home institutionalizations.

I think it would be worth adding at this point, since I did not cover it in my statement, that although we were dealing with a medicare-eligible population, some patients were medicaid eligible, and we received data on their medicaid utilization as well—that is, their long-term nursing home use, and other things—from three of the four sites we studied. In no instance was there a signficant use of medicaid institutionalization either.

Mr. **Bonker**. Well, let us shift for a moment over to the social aspect of day care centers. This question would be directed to either Ms. Klapfish, or Mr. Reed, and I am interested in the differences in services that one may find between a day care center envisioned under this concept, and under senior citizen centers as we know them today.

Ms. **Klapfish**. I will respond first to that question.

In senior centers in Massachusetts, there is normally no health care staff.

Mr. **Bonker**. No, I am not talking about health. There are two different concepts under adult day care centers. One is strictly for health requiring some kind of skilled nursing care; the other is for social purposes.

Ms. **Klapfish**. I don't agree with the statement in your question. The way I see it, there are two models. There is a health model, that I would call a wholistic model, that combines health and social services. Then if you are going to make the distinction of social model, there is a social model that has no health services at all in it.

Mr. **Bonker**. OK. That is the model I am interested in for this question.

Ms. **Klapfish**. I think the social model is a very controversial issue. I think that for the client who primarily needs a structured environment, supervision, for example, a chronic wanderer, people who may have mild dementia problems, some of the health services may not be necessary, at least to the degree that they are offered in a health oriented program.

I personally think, and in no way is this representative of how most of the field might think, that senior centers can be adapted with an additional staff person to have a small social program within the context of the senior center. Funding would have to be appropriated for this additional staff person.

Mr. **Bonker**. Well, senior centers have social programs now.

Ms. **Klapfish**. They do not have supervised structured programs, and that is the real difference.

Mr. **Bonker**. But what you are looking for is a source of revenue to put on another staff person on an existing senior citizen facility.

Ms. **Klapfish**. I think for a social program, it would be possible to build into a senior citizen program that is going now, a component that is more structured with money for additional staff.

Mr. **Bonker**. But can you not do that merely by modifying the existing program for centers? I mean, why set up a whole new senior center for social programs when you have an existing one?

Ms. **Klapfish**. That is not what I am advocating. What I am advocating is taking your senior center that exists now, and adding a new program component into that center. For example, I was the director of a title VII nutrition program senior center for a number of years. People wandered in at 7 to 11 o'clock in the morning, 60 to 80 people came to that program a day. There was one staff person, and that was me. There was no way that if I had people who were chronic wanderers, who were confused people who needed structured programing, that I could have done anything for that group of people. That is what your senior center looks like. The person who needs, let us say social day care if there is such an animal, cannot be in the typical senior center environment. They need something more structured, so you would therefore have to add at least one staff person to be responsible for a cluster group within the larger group.

Mr. **Bonker**. OK. I think that is something that has to be addressed, probably at the local level, or area aging level, depending on what resources they have, and how they are going to balance out those resources and services as the local administrators see fit. But I just do not see an adult day care center as an alternative to the existing senior center. I hope that is not what is being advocated. We are having a hard enough time getting senior centers established in various communities throughout the country.

Ms. **Klapfish**. I think that somewhere, if you have got this impression our testimony has led you astray. In viewing a continuum of care, you have a person who is in a senior center who is a relatively active, well person——

Mr. **Bonker**. OK. I understand what you are saying. In looking over staff material they say that there are two types of adult day care centers. OK. One is for health related, and the other is for social.

Ms. **Klapfish**. I think that then your staff has informed you not completely enough of the situation.

Mr. **Bonker**. So we are just talking basically about health oriented centers then, not social. I mean, there would probably be some social benefits that will come into play if we have such a program for health care.

Ms. **Klapfish**. It is just not that black and white. I think that maybe the classic example is you take a person who is a stroke victim. Yes, in a health oriented program there is a whole range of health services to help deal with that person's problems. You have physical therapy, occupational therapy, and in many instances speech therapy. You have nursing supervision to monitor vital signs, et cetera. One of the common results of a stroke, as Mr. Wood, I believe, in the earlier testimony stated, is that you get very depressed. You lose your sense of self worth. You become very, very dependent. You are not like you used to be all of a sudden. A stroke is not a slow sort of transition. It is fast, usually. That is where the social service element is inseparable from a program that you are labeling as strictly health. You have to have the social and recreational interaction, the social service counseling component. Social service and socialization components are as important as the health care. The one thing that you cannot do is uniquely separate health care and social services in defining a health oriented program.

Mr. **Bonker**. OK. I will get off that limb of the tree on to another.

In reviewing your response, Mr. Reed, I notice in question 3 that I have here, you state that there is no consensus across the State that day care is cost beneficial. My question is, Who are those in the State who feel that the program is not beneficial?

Mr. **Reed**. Well, it is really the area agencies. In our State, all of the money for day health is allocated to area agencies for administration, the State money, the title XX money, and then title XIX is handled a little bit differently. The area agencies, through their planning process, decide how that money can best be spent in any community, and while most of the area agencies have concluded that it is cost beneficial to have that element of continuum care in their community, all have not decided that yet. Some feel they can deliver services in other ways. Some feel that it is not feasible to have a day health program, or day care program because of the size of the community. The day care program is primarily an urban type of service delivery model. If you have large rural areas, for example, Klickitat County in our State, it is very difficult to have one central site that you bring people into for day care because the transportation involved is so great that that is not cost effective.

I think it is primarily that issue about the large territory to be covered to bring people into a centralized program for service, even though there may be many individuals, or several individuals that live in that large rural area that need day care service, there are not enough to justify the cost to set up a center.

Mr. **Bonker**. I posed a question earlier to Mr. Weissert about the comparison of day care centers and nursing homes, and whether or not day care does provide an alternative, or substitute to nursing home care.

In this questionnaire that we sent out earlier, to which you responded, we asked how many persons could be diverted from nursing home care if adult day care were fully funded in your State, and you replied you did not know. Do you have any idea?

Mr. **Reed**. Well, what we do know is that based on the data that is available, that 12,000 people are in need of day care services, and we can assume that at least—I think the literature might say that at least half of those people are really on the verge of going to an institution right now, that many people could be deterred from a nursing home if they have the family support, or community support, whatever, to keep them in their own homes. We really do not have that information. That is one of the pieces that is lacking. There just has not been that kind of research done.

Mr. **Bonker**. So you do not feel in your own mind that having adult care centers will duplicate existing services and facilities.

Mr. **Reed**. No, I do not. I think that they really are an alternative to those people that need that alternative to maintain themselves in their own homes.

Mr. **Bonker**. Alternative to what?

Mr. **Reed**. Alternative to premature or inappropriate institutionalization. There are definitely people that need nursing home care, and need to go there. There is no alternative to that, but there are people that are currently residing in nursing homes, and going to nursing homes every day that really do not need to go there yet.

There has also been a number of studies done nationally that range from 12 to 30–35 percent of people being inappropriately placed in nursing homes, and one reason for that is perhaps that there are not community resources to help that person maintain themself in their own home. Most older people, I think, really prefer to stay in their own home where there are those resources in the community, to help them stay there.

Mr. **Bonker**. But still, I am troubled by Dr. Weissert's conclusion. Three-quarters of the recipient patients are the walk-ins, did not come from the hospital, and were probably not headed for nursing home care, but were merely referrals. I am not saying there is not a demonstrated need for the program. I am just trying to understand whether or not the service is indeed a substitute to an existing service, because at some point you are going to draw away from the resources that are supporting the existing programs, many of which are not even doing a satisfactory job now, but I guess we are going to need further study on this matter.

Mr. **Reed**. I think that is the issue. I think it is important that we do have program standards at the State level, I believe, rather than at the Federal level, to have a definite understanding of what a day care program is so that when we do that kind of research or survey, that we can determine what we are talking about, because that does not exist now.

Mr. **Bonker**. I, speaking as one Member of Congress, I am not sure if I would support further Federal funding for these programs until we have a better understanding of how effective they are in relationship to other programs.

Let me ask you about this; the Federal Government also funds programs for nursing home care, and home health services. Now, if we are talking about a person who is in need of some kind of skilled care or therapy, presently if it is part of inpatient care in a hospital they can go to a nursing home and receive that service, or a further extension is home health care service. They can have a nurse actually visit them. You would recommend a third option, and that is adult health care centers. Now, is it not possible, short of that, for us to have nursing homes provide that kind of so-called outpatient service so that a person could actually drop into a nursing home where they have skilled care, and they have the facilities to receive that kind of in-house service, or expand home health service of therapy, or if some kind of nursing care is required, it should be available there.

My problem is that we are adding a new program that may, or may not be an alternative, but at some point we, in the Federal Government, are going to have to be sure that it is cost effective. There is a strong mood in Congress to cut spending, and I am not sure that we ought to be developing new programs, or expanding funding to support new or experimental programs, instead of being more effective with the existing programs.

Mr. **Reed**. I agree with that, and I have no problem at all in the State of Washington. If there is a nursing home that exists that wants to offer day health that meets our standard, we would contract with them.

Mr. **Bonker**. Well, what standards would you have in addition to what a nursing home is now required to provide under title XVIII?

Mr. **Reed**. Well, there are a number of different standards that they have to provide the rehabilitative services to the people that reside—not reside—but attend the day care program. The nursing home has that capability.

Mr. **Bonker**. Give me an example of a service.

Mr. **Reed.** OK; rehabilitative nursing, occupational therapy.

Mr. **Bonker.** What is relocative nursing?

Mr. **Reed.** No, rehabilitative nursing, occupational therapy. It is true that nursing homes can provide that, but they are currently, I would assume, providing that service to people that reside in the nursing home.

Mr. **Bonker.** Well, if they are providing it to the residents, can they not also provide it for people who come in?

Mr. **Reed.** That is correct. It will take more money to hire more people in that nursing home to provide that same service though.

Mr. **Bonker.** Why? I mean, if you are going to set up a new facility and staff it, you need an administrator, a director, nurses, therapists, aides, and so forth, and I am trying to look at whether this Federal dollar is going to be effectively spent. It is a very honest concern.

Mr. **Reed.** I appreciate that concern.

Mr. **Bonker.** You are setting up a new facility with this specialized help, including a director, and I am asking whether an established nursing home that would have the space, could utilize their existing facility and specialized people to provide the same service.

Mr. **Reed.** And the answer is "Yes." If they have additional specialized people to provide the service to the additional workload that is going to be there. There is no problem at all with housing it in the nursing home; no problem whatsoever, and we would be more than happy to do that. In fact, in one day health program in our State, it is based in a congregate care facility. That is the one in Spokane, and they do use some of the staff, occupational therapist, physical therapist, from that congregate care facility, to work in the day health program, but it is an additional workload that has to be paid for with another source of funds.

Mr. **Bonker.** Do you have an idea of the cost comparison between the two?

Mr. **Reed.** Well, I really do not.

Mr. **Bonker.** OK. Well, maybe it is something that we ought to pursue at some point.

Just a few questions, Dr. Weissert, and then we have got to get on to another panel.

You obviously have done a lot of work in this area, and your study, is fairly provocative. Did you come into this subject with a bias one way or the other? I have known you a long time, and you have always been a strong advocate of health care programs for senior citizens. Your position is a rather surprising revelation, at least for me.

Dr. **Weissert.** Well, as a researcher, I came into it without a bias. As someone making career choices, for example, when I did the first study of adult day care, I had been working on a number of social program evaluations at the time, I was very impressed with day care. It looked to me as if we had here a potential for a real solution to a real problem. I think we have found, in looking at many of the programs that we thought were real winners over the last couple of decades, that often we were offering nonsolutions to nonproblems. Day care looked to me like it was the real potential for great benefit, and so I have really committed the last 6 years of my career to studying day care. I would not place myself in a class, in terms of an adocate, with people like Marie-Louise Ansak, who has devoted her career and all of her waking minutes to making a program operate, for example. But certainly, if I had a bias, it is in favor of day care. And let me just say this, that I looked at the data I have every way from Sunday before I drew the conclusion that there was no significant benefit.

Mr. **Bonker**. Well, now your study was from 1974 to 1977. That is 3 to 5 years ago. I wonder how it would apply today's state of the art.

Dr. **Weissert**. I think that is a worthwhile question, and I do not know the answer to that. The answer for a researcher is always, "Well, do it again." For a policymaker, you have to make the choice, I think, whether or not you have enough information to make a judgment, and I guess my answer to you is we do not—my personal opinion is we do not have enough knowledge at this point to make a judgment, and we ought to be very, very cautious about expansion of this benefit before we have better, more current evidence that it is beneficial.

I would add, the work you are doing now on studies of this type, will not be available for several years, either.

Mr. **Bonker**. I would like to apologize to the witnesses, and the audience, but I was to be relieved of my chairmanship an hour ago, and I have appointments backing up, and despite the fact we have 40-some people on this committee, it is very difficult to get someone to come in and Chair a session.

I have further questions, Dr. Weissert, but I think it is best that we move on.

I will be submitting questions to each of the witnesses in written form, and hopefully for your responses, because I think the question is going to come before the Congress at some point, and if we are going to proceed with an expanded role of the Federal Government in day care centers, then we have got to have as much information as possible.

It has been a good session. You have all been excellent witneses. I think you have really contributed to our understanding of this important subject, so I would like to once again thank you for your appearance today.

The subcommittee will now recess for approximately 20 minutes, and pick up at 1:30, and we have one remaining panel—two remaining panels, including representatives from the administration.

[The subcommittee recessed at 1:06 p.m., to reconvene at 1:30 p.m.]

AFTERNOON SESSION

Mr. **Ford** [presiding]. The committee will now come to order. The Subcommittee on Health and Long-Term Care, Select Committee on Aging is resuming its afternoon session.

Our next panel is made up of directors of various models and day care programs. First the Chair would like to recognize Ms. Marie Ansak, the executive director of On Lok Senior Citizen Health Services in San Francisco, Calif. Then we will hear from Mr. Dan Driscoll, director of the Special Community Services of the Waxter Center for Senior Citizens in Baltimore, Md. Mr. Driscoll also serves as chairman of the National Institute of Day Care, a program of the National Council on the Aging. Finally, we will hear

Mr. Howard Bram, executive director of the Menorah Park Jewish Home for the Aged in Beachwood, Ohio.

The Chair will now recognize Louise Ansak.

STATEMENT OF MARIE-LOUISE ANSAK, EXECUTIVE DIRECTOR, ON LOK SENIOR HEALTH SERVICES, SAN FRANCISCO, CALIF.

Mrs. **Ansak**. Thank you, Mr. Ford.

First of all, I am sorry that Mr. Bonker is not here because I have a lot of answers to some of Mr. Weissert's statements, and I think just in general before I go into my own testimony, I would like to say that I would like to submit a paper which was prepared by our research director Dr. Zawanski titled, "Methological Constraints on the Medicare 222 Day Care Demonstration Project," which goes into some of the problems that project presented.

One of the statements that Mr. Weissert made is that the day care centers used in the project were all experienced day care centers when they got involved in the 222 project. Let me tell you the ones in San Francisco—which I know intimately—got started one day before the 222 contract was entered into. I do not think you can call that an experienced day care center. I think it is important, and I think Mr. Weissert did say that perhaps further studies should be done, and I think this committee should look into that. The committee should also be looking at all the day care centers presently operating instead of just four very questionable programs which lasted for 1 year. I do not think that the Congress is going to get any adequate picture of day care, or care for the elderly if we look at projects that have lasted barely 1 year.

On Lok started as a day health center for the frail elderly in March of 1973 as a partial answer to the total lack of nursing home or long-term care facilities in San Francisco's Chinatown North Beach District. Over the past 7 years, this nonprofit community-based program has expanded its services from a limited day health program into a community care organization offering total health and social services to elderly over 55 who are sick, or handicapped and, very important, certified by the Department of Health Services in California as needing at least intermediate type nursing home care. So these people would have gone to nursing homes if they did not come to On Lok.

For the purpose of this hearing, I would like to limit my observations to the Day Health Center part of our program.

The day health center, which was modeled after the English Day Hospital, opened its doors in 1973 in an old remodeled bar. From the beginning a multidisciplinary team, composed of, at a minimum, a social worker, nurse, physician, and physical and occupational therapists, evaluated and reevaluated individual participants and offered direct services to them at the center. Participants needing medical and nursing supervision and/or rehabilitation services were accepted and scheduled to come to the center from 1 to 7 days a week. The main goal of the program was, and still is, to keep patients in their own homes, and assist them in being as independent as possible. They are, if needed, picked up by the On Lok transportation, brought to the center, and returned to their homes. At the center they receive their individual therapeutic treatments, meals, social work consultation, personal care such as showers, nail cutting, grooming, and are involved in various social and recreational activities.

Initially, and until 1979, day health services were offered in cooperation with the participants' private physicians. It is interesting to note that the On Lok program from the beginning has been quite popular with participants who joined the project, but that an enormous amount of educational work had to be done with physicians and families. The traditional care system for the elderly is geared to institutionalization. Both professionals and lay people need a total reeducation. We continuously need to point out that some weakness, forgetfulness, or even incontinence are no reasons for condemning our elderly to a life in a strange place away from home.

On Lok's day health centers are licensed for from 50 to 60 participants a day. They are full every day. At the present time we are serving a total of 220 individuals. Our costs for the day health center alone, which includes all services mentioned, run between $25 and $26 a day. In our negotiations with the California Department of Health Services in 1978, we were able to document that savings of up to $448.41 per month, or over $5,300 per year, per participant, could be achieved with the development of community-based day health centers. Today, the average medical reimbursement per day of the licensed centers in California is $21.18. There are some adders, so it comes up, for some of them, to $25. Also, there is some difference between the actual cost and the reimbursement.

In California, a distinction is made between the medically oriented day health centers and the social day care programs. This distinction is somewhat unfortunate and is due only to the vagaries of our reimbursement or funding systems. It is one of the most unfortunate facts of life that we still do not have a single coordinated funding source for long-term care. Day care, or day health services are each one small component of a continuum of care which in turn represents long-term care. The distinction between the need for day care, or day health is often difficult to make and depends more on the participants' particular health status on a given day. With the rapid changes in health being the norm for the elderly, centers should be able to offer all options and gear treatment plans to the needs of the individual. However, no center can do a satisfactory job without the backup of all components of the continuum of care from the senior center to the acute hospital or hospice program.

It is for this reason that On Lok has moved on and developed all the components of the long-term care continuum. Within one agency we are at the present time at the beginning of an exciting new development, and we hope to be able to share some encouraging news with you in the coming years. We are starting to find that the community-based continuum of care might not only be more satisfying to the elderly, but also significantly more cost effective. It is too early to submit data since our inpatient service component only started in February of this year. We have, however, been surprised at the significantly lower than expected use of hospitalizations. We are still waiting to add special sheltered housing as another component of our continuum this summer. By spring or early summer of 1981 we hope to be able to start to compile some figures on our initial experience with this system.

Thank you.

Mr. **Ford**. Thank you very much.

Mrs. **Ansak**. I also have to submit one letter which is addressed to the Honorable Claude Pepper, and which is supporting day health services, and signed by about 15 individuals who are involved in day care, and one of the State planning directors, et cetera, who would like the committee to consider day care.

Mr. **Ford**. Without objection, it will be made a part of the record, and let me say that the chairman of the committee is at home with a cold, or the flu, and he cannot be here. Other than that, the distinguished chairman would, in fact, be here today. Thank you.

[See appendix p. 85 for material submitted by Ms. Ansak.]

Mr. **Ford**. The Chair now recognizes Mr. Driscoll.

STATEMENT OF DANIEL D. DRISCOLL, CHAIRMAN, NATIONAL INSTITUTE ON ADULT DAY CARE; DIRECTOR, SPECIAL CARE SERVICES, WAXTER CENTER FOR SENIOR CITIZENS, BALTIMORE, MD.

Mr. **Driscoll**. Thank you, Mr. Ford, and distinguished members of the House Subcommittee on Health and Long Term Care.

This afternoon I would like to briefly describe the Waxter Center's day care program, and highlight some of the concerns and recommendations of the National Institute on Adult Daycare.

As a program of the National Council on the Aging, NIAD represents an affiliate membership of over 500 persons involved with, and interested in day are for the elderly.

The Waxter Center is a large, municipal, multipurpose senior center located on the fringe of downtown Baltimore. The center opened its doors in 1974 and now operates 7 days a week as a focal point of service to Baltimore's senior citizens, serving a current membership of over 15,000 persons. It offers a full range of services designed to keep the elderly well, active, and independent.

As a component of the Waxter Center, our day care program is a structured rehabilitative program for the impaired elderly. It is designed for those persons who are disabled emotionally, physically, or socially to such a degree that they are unable to function independently. The program participants, or members as they are also members of the senior center, present a variety of problems ranging from severe and chronic physical and mental handicaps to an array of multiple social and health-related problems. It is to be noted that this population is significantly more impaired, and therefore somewhat different from the membership served through the regular senior center programs and activities. The day care program serves an average of about 18 persons per day, with the total enrollment of approximately 40 different persons.

The prime objective of the day care program is to assist those elderly persons whose impairments prohibit living independently without supportive services, to reach and/or maintain their own maximum potential for independent living as an alternative to inappropriate institutionalization.

There are several purposes that the program is designed to meet: to reduce isolation and immobility; to stimulate interests in leisure activities; to provide opportunities for socialization and coming together in a group setting; to enhance activities of daily living with instruction in self-care, health maintenance, consumer protection, and assistance with accessing to other community services as needed by the individual; to improve health status by maintaining necessary liaison with providers of health care, and to coordinate care and counseling with the person's family, thus providing support and assistance to the individual's care giver.

Admission to the program is based on a comprehensive, professional assessment which includes evaluation of both physical and mental health status, and of the person's environmental and social situations. A functional assessment is completed on each person, which draws a profile of the participant's performance in tasks of daily living. An individual care plan is developed from this information outlining the needs of the participant. This care plan is revised and refined as the person's needs change over time.

The day care program, in a protective setting within the larger framework of the senior center, provides a wide range of activities. They are planned in order to assure that the person receives the services that are needed without overserving, and ties in with the full range of the resources of the Waxter Center with all the senior center facilities, services and resources available to the participants of the day care program.

Discharge from the day care program is a possible goal that is considered even at the point of admission. In those cases where progress to greater independence seems indicated, ongoing planning for discharge is made with the client.

As a component of the senior center, the day care program is unique in its ability to bring the impaired older person into contact and relationship with their well peers. These types of experiences provide incentive and motivation toward improvement for the disabled older person who is participating in the day care program.

From the national perspective, there are several issues which I would like to highlight.

In this era where the key words are coordination and cost containment, adult day care is beginning to show many exciting ways to approach these problems. It is an important component of the continuum of services, which is perhaps most strikingly indicated by the very fact that day care has not developed from the top down, but rather it has been a grassroots movement born out of real community need, and sponsored by a wide variety of public and private resources. It adapts to, and ties in with other resources available within the local community.

As we know, the number of day care programs has increased significantly during the past several years with only minimal assistance and direction from the Federal sector. To encourage continued development of this needed service, the National Institute on Adult Day Care would like to recommend the following for the committee's consideration:

First, legislative and executive action to remove the barriers to the integrated use of funds of medicare, medicaid, and title XX social service dollars to support day care programs. Federal mechanisms are needed to encourage the increased use of funds for the expansion and effective implementation of day care as a service option.

Second, uniform standards be developed to serve as a model for the delivery of quality day care services. We are not referring only, or necessarily to regulations, but a baseline framework that can be used as service providers throughout the country are developing day care programs to respond to local community needs. An exploratory survey conducted recently by NIAD has confirmed that standards of operation vary tremendously among the States. While 30 States do have established standards, over half are designed for funding purposes only, and do not really adequately address the programmatic and quality control factors of service delivery. In the historical model of the senior center field and vocational rehabilitation services, it is further recommended that practitioners be intimately involved in this process. Workers in the field of day care are sensitive to the needs of the day care clients, and from experience can serve as a vehicle for this standards development.

Third, that additional and expanded evaluation of day care be undertaken. We feel we must look at what is currently being done, what are the variations in practice, and what is the potential of this service option. Policy cannot be made on existing limited data. There has been a tendency to compare apples and oranges instead of what the real costs would be to society if adult day care participants had to receive all these services which are available at the center through other sources. Day care is currently operating in 43 States, which suggests there is already sufficient experience to confirm that it is viable, and a needed service. We believe this delivery of service should not be interrupted for the sake of research, but rather evaluation should be designed for further development ongoing along with practice.

Finally, we recommend the designation of a single Federal agency which will have the responsibility for the evaluation and enhancement of further development of this service option. Coordination of activities in regard to day care must be effected to better enable practitioners on the frontline to negotiate the labyrinth of Federal agencies, acronyms, and such, in their efforts to deliver services to the most vulnerable segment of the aging population.

I would like to thank the committee for this opportunity of testifying this afternoon. We feel, and believe strongly that this hearing is a milestone in the day care field, and in the day care movement, and are much appreciative of this opportunity.

Thank you very much.

Mr. FORD. Thank you very much.

The Chair will recognize the very able colleague of ours, Congresswoman Oakar, for the introduction, of Mr. Bram.

Ms. OAKAR. Thank you very much, Mr. Chairman, and I want to commend you and Senator Pepper, and other members of the committee for having this very, very important hearing today.

I am very pleased, Mr. Chairman, to have the committee hear from someone who is very well known in the Greater Cleveland area in terms of the field of geriatrics, and I believe also is a national figure in terms of expert care. I am speaking of Howard Bram, who is the executive director of Menorah Park Jewish Home for the Aged. This is a geriatric center that has been in our area, Greater Cleveland, for almost 75 years, and they have been innovative in the field of day care centers, having begun one in 1968, so I believe they are among the first in the country to start a program, and they have added to the program ever since. So it gives me a great deal of pleasure, Mr. Chairman, and thank you very much for that courtesy of hearing from Howard Bram, the executive director of Menorah Park, and we are very pleased that Howard could come today.

STATEMENT OF HOWARD B. BRAM, EXECUTIVE DIRECTOR, MENORAH PARK JEWISH HOME FOR THE AGED, BEACHWOOD, OHIO

Mr. **Bram**. Thank you, Ms. Oakar.

We had Ms. Oakar's special assistant on aging meet with a group of day care directors at Menorah Park just a week ago, and she addressed the group and participated in the discussion, I think there were 12 day care directors who were in attendance for a half-day institute.

Menorah Park is a geriatric facility located in Cleveland. We are located on a 40-acre site which is now the fourth location we have occupied in the past 75 years.

We are deeply committed to serving the frail and the impaired elderly, and are equally committed to developing noninstitutional services. We believe that people ought not to be entering long-term-care facility if it is avoidable, and we do everything we possibly can to help people remain in the community. Therefore, on the grounds of our geriatrics center, we have a highly skilled long-term-care facility, with 285 long-term-care beds. We have 235 people residing in a congregate housing facility. We have 125 who are enrolled in our home delivered meals program, 98 in our adult day care program, 22 in our day care program for the severly handicapped; 30 in our religious holiday stay program; 20 in our vacation stay respite program, for a total of 815 different persons served.

We now have on the drawing boards a psychiatric evaluation center, a respite program for the severely impaired, and a day care center specially designed to handle the severely mentally impaired person.

I have been invited today because I represent the long-term care facility based day care programs. We have two such programs. In Ohio, there is no medicaid support of adult day care, so we must be entirely funded by private philantropy.

Our adult day care program serves the frail, and the moderately handicapped older person. This program was established in 1968. The people in this program are in their middle eighties, very frail, very fragile, many using walkers, or using wheelchairs, but able to function on a rather good level.

We then have a second day care program for the severely handicapped. That was established 3 years ago. Both programs are housed within a specially constructed single, self-contained day care center which is located in the middle of our long-term-care facility. It has 3,000 square feet. It has a separate entrance to the outside with bus unloading and loading area to bring the people to the program, a couple of lounges, dining rooms, resting rooms, a pantry, toilet facilities, bathing areas, et cetera. The day care center has direct access to the center of our long-term-care facility, to our occupational therapy and physical therapy departments, to our sheltered workshop, to our beauty parlors, to all of the services available to the permanent residents of the long-term-care facility. They share them.

First, let me describe the adult day care program. I mentioned earlier that it serves a very old population. Its average age is well into the eighties. We do have a few wheelchairs in this program, but they are the kind of wheelchair patient who is able to get onto a bus, managing the steps with the help of two assistants. Those who join this program do so because of a need for socialization, counseling, nutrition, personal care, and rehabilitation.

To clear up some of the problems we had in the earlier testimony in terms of definition, this group is too old, and too frail to participate in the usual senior citizen center. I would like to get into this subject further later on in the testimony.

Most of the people in this program live by themselves. Others live with their children, or other relatives. Participation in the program enables them to remain within the community, or to prepare for admission into a long-term-care facility, or to help them cope in the community while they are on the waiting list awaiting admission to the home. We have found that with our many years of experience, that 54 percent of the participants have been in the program from 2 to 9 years, so that I believe we have succeeded in keeping them within the community.

Now, the day care program for severely handicapped is also known in parlance as the "day hospital." Particularly in England where they invented the term, "day hospital." We have chosen not to use that terminology because we believe it is a misnomer. Hospitals deal primarily with acute illness. Day care business is dealing with chronically and permanently disabled people, not people who are presently acutely ill.

This severely impaired program serves those who are unable to ambulate because of handicaps resulting from a severe stroke, single or double amputation, advanced multiple sclerosis, crippling arthritis, injury from accidents, and other disabling diseases. In this program the average age is considerably less than it is for our adult day care program since we do have several people in their thirties, forties, and fifties, suffering from multiple sclerosis, or some injury which has caused severe handicap. There are 22 people in this program presently, with an average of 8 attending per day. Almost all of the participants are residing with either a spouse, or children. Their attendance in this program not only gives them temporary freedom from the imprisonment of their own homes, but even more so, a degree of respite to their care givers. I would like to repeat this. I think respite is one of the major objectives of a day care program; that is, to give respite to those who are struggling so hard, the spouse, the children, other relatives who continue to care for a disabled person within their own home. Intensive rehabilitation and personal care are important aspects of this program.

I was asked, too, to identify what are the service components of a day care program. Let me take a crack at that now.

TRANSPORTATION

Transportation is a necessity of the program. People must be able to come to the program by a method designed by the program sponsors. We use two, and occasionally three schoolbuses with drivers. These buses are leased each day to pick up the adult day care program participants. In this program the driver must pull up in front of the house, must get out of the bus, go to the front door and assist the participant from the house to the bus, and onto the bus. The reverse occurs on the return home. For that reason, it becomes a very costly process. You cannot pick up more than perhaps 8 or 10 persons with any one bus, otherwise they will be spending half the day on the bus.

In the case of our severely handicapped program, an entirely different transportation system is used. Our own health care attendants drive the center's own special bus equipped with hydraulic lift, and all of the other necessary equipment. They pick up the participants and return them home at the end of the day. In this program, the two attendants go into the house and literally carry the participant out of the house to the bus, often down a long flight of steps.

MEALS

The adult day care program serves a continental breakfast, lunch, and dinner, that is three meals a day to all of its participants, and will even give a home delivered meal package to a participant to take home with her or him for additional meals during the week or the weekend. The handicapped program participants spend a shorter day at the center. They are served only two meals, a continental breakfast and lunch.

Personal care becomes another important component, and the adult day care participants may use the beauty parlor or barber shop. If not for their availability they would usually not be able to get to one. They may also be bathed if it is not possible for them to do so within their own homes. Some may need assistance with toileting. However, in the day care for handicapped program, all of the participants are bathed in our special whirlpool century tub equipment. They receive toenail and fingernail care, use of beauty parlor or barbershop, and almost all must be assisted with toileting. Now, a very significant factor is this bathing service is that almost everyone who is in our day care for the handicapped program has not been in a bathtub for several years. When they came to our program we are able to get them into a bathtub with the special equipment that we have. They are so disabled that their care givers just do not have the strength to do it at home.

Counseling becomes a very important part of the program. Our two programs are headed by graduate social workers who provide counseling to the program participants and their families. In the case of the handicapped program, the families meet one evening per month for group therapy sessions to help them cope with their tasks of care giving to a handicapped person.

Physical therapy is offered each day to each of the handicapped persons, and selectively to those in the adult day care program. The prescription for therapy must be provided by their own private physician.

OCCUPATIONAL THERAPY

Each participant in the handicapped program, and some within the adult day care program are evaluated by the registered occupational therapist to determine how this program might best be used for their rehabilitation.

ARTS AND CRAFTS

Many persons from both programs use this activity and benefit greatly from the diversion and sense of accomplishment.

One of the things that is rather unique at our facility is that we have a sheltered workshop in which we employ 100 of our residents, average age around 87, who work 25 hours a week on industrial projects. Many are people in wheelchairs totally disabled. Many of the participants in the day care programs work in the sheltered workshop performing assembly work for which they are reimbursed. In this work therapy program they continue to work within industry; they feel worthwhile and a vital part of the economy.

Volunteers are an essential ingredient in the success of this program. The volunteer brings the devotion and freshness of the lay person, and helps to keep the cost of the program down while adding considerably to the personal services available.

NAPPING

Contrary to the assumption of the uninitiated, resting or napping is not—and I will repeat—is not a desirable service to offer in these programs, and we do not encourage it. The aged and infirm should have a full day of activity and go home tired so that they may sleep well during the night, and not walk around all night. We do have a few small resting rooms for an occasional rest for a small number of selected participants, usually no more than 5 percent of our population.

We have cooking and baking classes for the handicapped. They are taught to prepare their own meals within their own homes with their handicaps. We provide them with the mechanical equipment they need in order to do this.

RECREATION

Recreation, of course, becomes a very important and essential part of any kind of day care program. We hold programs each afternoon of a recreational and cultural nature.

MEDICATION

The participants bring their own medication to the office, and are then reminded by the day center staff when they are to take their medication. If we were to dispense medication in Ohio, we would need to be licensed to do so. It would create a whole new documentation necessity, and I think it is wise that day centers stay out of this. They should use only the medication reminder system.

NURSING CARE

We have a nurse who works part time for the program. She teaches the elderly and the disabled how to function at the highest possible level. She conducts exercise programs each day. An educational session is held once each week to promote good health and nutrition. Blood pressure and other vital signs are taken on a regular basis. If the nurse suspects a change in the participant's health condition, she will call his or her private physician to inform him of the suspected change.

EMERGENCY CARE

With a very old and fragile population like this, we have heart attacks, strokes, fractured hips, happening at the day center. If a participant becomes acutely ill our professional staff, within the long-term-care facility, renders lifesaving care in our own acute care division until the private physician can arrange transfer to the general hospital.

The per diem cost of operating our adult day care program is $20.40, including transportation. A breakdown of those costs are 40 percent for personnel; 34 percent for transportation; 16 percent for food; and 10 percent for the remainder. Transportation itself amounts to $6.50 per diem, and is one of the major cost factors.

We charge fees on a sliding scale basis according to ability to pay. The highest fee paid for our adult day care program is $15. Most of the people served in the program are on marginal incomes, paying what they can afford, some as low as $1 per diem. The total received last year in fees was $37,000, out of a total cost of program of $108,000. The $71,000 deficit is made up from philanthropic funds plus contributions inkind from the long-term-care facility.

Now, for our day care for the handicapped program. The cost is slightly more than twice what it is for the adult day care program. The cost is $41.40. This higher cost is primarily the result of the high ratio of staff to participants. The participants are so completely disabled that we need a ratio of one staff person to every two persons served in the program.

The major problem faced by our program presently is financing. With the severe inflation, the participants who are on marginal income are finding it more and more difficult each year to contribute toward the per diem charge, and the average per diem payment which we are receiving is going down every year, while the costs continue to rise. The population served also is becoming more frail, and more confused, and we find that the handling of confusion is a serious matter. That is why we are presently studying the possibility of creating an entirely new day care program designed only for the mentally impaired.

It becomes more apparent to us that we will need assistance from Government sources if the program is to continue, inasmuch as philanthropic funds are limited and level of giving has plateaued. We have applied to the area office on aging for assistance under title III and title XX, but with the inflation the Administration on Aging is finding it possible only to continue to fund programs which they have already sponsored, and we have not been successful to date in being included for funding.

If transportation services for the elderly and handicapped, under publicly funded programs, were available to us at no cost, or at a token cost, it would substantially reduce our deficit and our reliance on philanthropic funds.

Being where I am in the long-term-care field, and being a geriatric center administrator, and being in the field for a very long time, I believe that having the day care program based at a long-term-care facility is possibly the best method of implementing a full program of care because of the availability of a wide range of services already located in the facility. As an example, when we provide physical therapy, we already have the program there. We have the equipment. We have the professional staff. They may need to work only an additional 1½, or 2 hours a day in order to serve the day care people in addition to the inresidents of the home, but they are there, and they are in place, and we do this with a whole range of programs. It is pretty hard to duplicate this in a freestanding day care center. Also, the personnel and administration are knowledgeable, and attuned to the needs of the frail and infirm.

And now, I would like to just take a minute to comment on what happened at the earlier testimony.

I think we have some problems with definition. The committee was concerned about the question of the social day care center, for example, as opposed to the adult day care center. I personally believe it is a mistake to use the terminology of a "social day care center," because all day care centers, no matter whom they serve, should have a strong social program. It is a necessary component of all of them. I believe the different levels of day care programs should be differentiated not by the program as much as by the condition of the people who are served. The traditional senior citizen center serves those people who are vigorous, healthy, who can get to and from the center by themselves generally. They may be coming only for recreational purposes or they may be coming for educational purposes, or for nutrition. The nutrition center would fall into this category.

You then move up the line, and you have the day care center which deals with the very frail, the very old, fragile type of person who is in his eighties and nineties. They are too frail to participate in the traditional senior center. They need a specialized kind of center, and they need more staff. The main difference is more staff, in order to handle the disability of the people involved.

You may then move a step further and deal with those who are severely impaired. When you deal with the severely impaired you continue to provide some of the same services, but only with a greater intensity of staff, and an intensity of program. There are other day care centers which deal with the mentally retarded. There are those which deal with the mentally ill and there are programs which deal with the mentally infirm. All of them are day centers, but each deal with a population that needs a different type of staff, and a different type of program, I believe this is the way we ought to be looking at the variety of programs available.

Thank you very much.

Mr. Ford. The committee would like to thank each panelist for giving their testimony today before the committee. I am going to have to leave, and I am going to ask the Congresswoman from Ohio to Chair the committee.

I would just like, for the record, for Mrs. Ansak to respond to maybe one or two questions; one being out of the 220 participants you talked about in your testimony before the committee today, how many of those 220 would be actually placed in nursing homes if On Lok did not exist; and also, if a large proportion of those would in fact be placed in nursing homes, then are you saying that the day health services is an alternative to the nursing homes; and also part 3 to that, out of that 220, do you have many minorities? If so, when you think in terms of black minorities, Indians, and other minorities, what about some of the programs that we are talking about in thinking in terms of the death rate, mortality not being as great, I mean lives not being as long as those of Caucasians, other groups, should there be any legislation in the future as to relate to agewise for different races, and all. If you would respond to those questions, I would appreciate it, Mrs. Ansak.

At this time, the Chair will ask Ms. Oakar to Chair the committee. Ms. Oakar.

Mrs. ANSAK. I will start with the last one first.

Mr. FORD. The last question is that we have a problem with the minorities not living as long as—black males, black females—not living as long as white females, and black males not living as long as white males, and I am just wondering when we are talking about these programs, and age groups and all, should we be talking about lowering the age requirements back for some of those who do not have the expectancy of life?

Mrs. ANSAK. Unfortunately, I am dealing with a different minority group, and that is the Chinese, and they have an enormously long life expectancy.

Mr. FORD. I understand that. When you think in terms of the Chinese people who have a long, long life span, how does that relate to other groups; maybe not your group directly. That is why I proposed a question as to how many minorities; are there any blacks, Indians, and other minority groups.

Thank you, Ms. Oakar.

Ms. OAKAR [presiding]. Thank you, Mr. Chairman.

Would you like to respond?

Mrs. ANSAK. Yes, I will try.

The population at On Lok is 70 percent Chinese, and the rest is a mixture of Caucasians, Filipinos, Italians, whatever; very different ethnic groups. Most of our participants are foreign born. I think it is now about 90 percent. It used to be 99 percent lately. We added a different area, and now have about 90 percent.

We have very few blacks because we are districted. In our district there are very few blacks, and very few American Indians. I have heard that there is a lowered life expectancy, among blacks and American Indians. Because of my lack of experience I cannot address myself to that question. The Chinese, and other participants in our program are on the average 80 years old. I think their life expectancy is about equivalent to Caucasians. But I think the problem should be considered.

Another thing which should be considered when you are talking about day health services. On Lok is restricted to accepting only people who need at least intermediate care. There might be an age limitation, and I think the Federal Council on Aging at one point suggested that frail elderly be entitled to services, I think it was age 75; I cannot recall exactly; but I think there should be a certain age when people are automatically eligible; but as to the problem of other minority groups, I cannot talk about it because of lack of experience.

One of the questions, another question was is—if I recall it right—does On Lok present an alternative—does the day health center at On Lok present an alternative to nursing home care, and what would happen if On Lok were closed. We have estimated at one point that 80 percent of our people would go to nursing homes if we would close. Within 3 months—I think that was the estimate—they would need nursing home care. Whether they would go or not is another question, because many people prefer to stay in their homes, and they decide they do not want to leave the area, particularly in our area where there is no nursing home. They would have to be removed 30–40 miles from the area. They would have to enter nursing homes where they cannot speak the language, eat their foods, et cetera. They would probably prefer to stay in their own home, but they would probably die. You know—it always seems to me when we are talking about cost effectiveness, well, the cheapest way is probably to die, is it not? But this issue is, I think a dangerous thing. Essentially I would say On Lok is an alternative to nursing home care.

At the present time, we provide all the services from the social day care center, all the way to hospitalization. We get a capitated rate, and therefore are really interested in looking at the service that keeps our participants in the community and independent as long as possible, and at the best possible price. We do not get more funds when things don't work out. So I think day health services, from our point of view are an alternative to nursing home care.

It is not an alternative for those people who need 24-hour nursing care and who are bedridden. There is absolutely no way, to get them to any health center, and those people should be in skilled nursing facilities.

There is another interesting observation. Sometimes when we have patients who need to go to a nursing home, the nursing homes refused them because they are too heavy care; and what does it end up with? We have to keep them in the community and bring them to the centers, and make all kinds of arrangements in the homes. I think that is a very interesting proposition, which I think the committee might want to look into, too. What kind of people do nursing homes take? They take those, at least in our area—I am speaking only for San Francisco—those who demand less care. When somebody is incontinent, it is very difficult to get somebody in the nursing home.

Ms. OAKAR. I wonder if you would just expand on that, just for the record. What is the alternative, though, because many of these people who need comprehensive care are from families that either are not available to them; they are alone, or possibly in some cases the families are indifferent toward their welfare; then what happens?

Mrs. Ansak. Sixty-five percent of the people at On Lok have no family, so I think we can speak to that. They are mostly living in rooming houses or hotels. This is why we have provided the continuum of care. We felt that, for instance, it was essential to add in-home services. Now, these in-home services might be very minimal. It might be to assist the person to make his bed, or to see to it that somebody is on the night shift and goes and checks that the person is actually in bed; will assist him to get up in the morning. All I want to restate is that of the people in our program, 65 percent are alone, and depend on a support system. That might be a housing manager, or a friend next door in the rooming house, et cetera.

Ms. Oakar. All right. Let me ask Mr. Driscoll one question, and that is how many clients are actually discharged as a result of improved health? You stated that that is one of your goals of your day care program at Waxter is the discharge of individual clients. Am I correct about that?

Mr. Driscoll. Yes, that is correct. Over time, I do not have the exact figure, but it would average about two, perhaps three a month. The day care program is small, and the process of discharge into the senior center is many times a lengthy process. We feel that there are ways in which the day care program interfaces, and can tie in with the senior center, while retaining its distinctness and providing a separate kind of programing, and separate kind of resources. The variables that come into play are the family supports, and many of the other things we have heard here, and the capabilities of the senior center.

In Baltimore we have had some very exciting experiences in looking at a continuum of service, one might say, with several—and I will use the term "models" for a working definition, or working terminology. In Maryland, and in Baltimore, the framework of day care is such that there are day treatment, and day care programs. The day treatment has a much stronger medical component; a much stronger rehabilitation component. In Baltimore, there is a day treatment program at the Public Health Service Hospital. We have had some very strong and close collaboration, and some exciting individual cases where a person has been admitted to the day treatment program after a traumatic illness, and has received intensive rehabilitative services through the hospital-based resources available there; the person has been able to be discharged from that program into the day care program at the Waxter Center, and over time is able to move to more independnent activity and participation in the senior center. I cite that because it is the kind of thing that is just very exciting to see what happens with the individual.

I think another aspect of the day care senior center kind of linkage is that a person is able to participate, and be a member, a participant in the day care program, but also then to be able to tie in, utilize, and participate more independently in other resources in other parts of the center.

For example, with the lunch program, in our center all of the members of the day care program have lunch in the communal dining room. It is provided through "Eating together in Baltimore," the title VII program, but this is an opportunity for the day care members to move from one part of the building to another, and to be with friends and peers. Staff support is needed in terms of preparing the meal, perhaps getting the meal, going through the cafeteria line, and so forth. The number that are discharged is significant. It is something we need to look at, but I think that equally important, we believe that the ability to be able to bring in the kind of services, and the kind of resources that meet what the person needs at that time, so that while a person may not officially, or technically be discharged, their plan of care in the day care program is minimal. It provides some coordination; it provides the linkage to more independent activities in the senior center, but coming back to base and having a home base, if you will, that they can move out from. So I just suggest that it be viewed in the broader framework.

Ms. **Oakar**. Thank you.

We are under a very tight time arrangement here because so many of us are on other committees, et cetera, and I know the committee will want to ask some of you to respond in your answers in writing. We will have other questions.

Let me just quickly ask Mr. Bram one question, and I think it is a question that all of you perhaps would like to respond to in writing, and that is would you like to apply for a public reimbursement if there were a unified funding source? Right now, you mentioned the State of Ohio does not have one. Do you feel that somehow we ought to have this a universal type of medicaid program, let us say, or make it a Federal program so the day care could be covered?

Mr. **Bram**. That is an interesting question, and I ponder it because I know the first instinct is to say yes, let us get the funding so that it would help us through our funding dilemma.

On the other hand, I feel that there are such misconceptions, such lack of knowledge, such lack of research, terminology, in this whole range of day care program services that it would be untimely now, in 1980, to try to create a universal program. I think that if HEW were given that responsibility now it would have a difficult time trying to design a method of reimbursement based upon appropriate standards.

Having been in the long-term care field for a number of years, and having felt the tremendous load of regulation that has accompanied the medicaid program, I would like to see a new way of developing day care reimbursement systems different than the conventional one used for medicare, and medicaid. I say this for the simple reason, that even though people in the program are chronically disabled, and will have this chronic disability the balance of their lives, the major emphasis in a day care program is socialization, the counseling, the activity, the loving tender care, nonmedical kinds of programs. Even though there might be some physical therapy rehabilitation, might be some taking of blood pressure, might be some medication administration, the emphasis ought not to be tied to a medical model. I think we need to design a new type of reimbursement system which recognizes that the greatest need, and the greatest disability of older people are their emotional needs, and their social needs. In order to assist them to cope with all of the illnesses and frailties of old age, we must recognize that everything is not medical. If we could design a system of reimbursement which would recognize this principal I think we would do much better.

What would happen if HEW were suddenly given a reimbursement program to design this year? It would find, I'm certain, enumerable ways to require compliance so that a major portion of the time of the staff would be diverted to document what they plan to do; how they are going to do it; what they have done; and what the results are; spending much of their time in meetings so that surveyors may come around to make sure that the money that the Federal Government has expended has been appropriately used. I am not being factitious; I am being very serious about this. I would hope that we would be able to design a program that would recognize, first of all, the nonmedical needs, and secondly an entirely different and simple method of reimbursement.

Ms. **Oakar**. Thank you very much, and I am sure your views are shared by many, not only in the audience, but across the country about the regulations of HEW.

I am going to thank you as a panel, and please know that the committee will submit some questions in writing to you, and thank you for being here.

I also would like to turn the Chair over to my distinguished colleague, Mr. Bonker. Thank you very much.

Mr. **Bonker** [presiding]. Our final panel consists of Administration spokespersons, Jeffrey Merrill, Michio Suzuki, and Kathryn Morrison.

I am sorry this hearing has extended beyond what we had planned for, and I am here again on extended time with some scheduling conflicts ahead.

I think it would be advisable that if you would submit your formal statements for the official record, and use whatever time that we have left to respond to some of the things that have occurred earlier today in the hearings. I know that at least one of you is anxious to clarify some of the things that have been discussed, and maybe respond to Dr. Weissert's study, which was discussed on earlier panels, or if you want, just summarize in whatever way you feel would be most effective. There are not many panel members here. I am about the only one, and you know my concerns, so you may want to address them more specifically.

I think what we will do is just allocate five minutes to each, and then proceed from there with questions. I apologize once again for the short time available, but knowing that you are high ranking members of the administration, you can summarize your statements effectively in the time that is available.

Mr. **Merrill**. Am I first on the list?

Mr. **Bonker**. I am sorry, Mr. Merrill is the Director of the Office of Legislation and Policy in the Health Care Financing Administration, and he will be our lead-off witness.

Mr. **Merrill**. Well, in keeping with what you have proposed, I will abandon my statement.

Mr. **Bonker**. You do not have to abandon it. We will put it in the record.

[The prepared statement of Mr. Merrill follows:]

PREPARED STATEMENT OF JEFFREY C. MERRILL, DIRECTOR, OFFICE OF LEGISLATION AND POLICY, HEALTH CARE FINANCING ADMINISTRATION

Mr. Chairman and committee members, I am Jeffrey C. Merrill, Director of the Office of Legislation and Policy in the Health CAre financing Administration I am pleased to be with you today to talk about the Health Care financing Administration's involvement in Adult Day Health Care Services. As you know, the Health Care Financing Administration is responsible for the administration of titles XVIII and XIX of the Social Security Act, commonly referred to as the Medicare and Medicaid programs. For this reason, we have a major interest and role within the Department in long-term care policy and program development. We are working closely with the Department Task Force, chaired by the Under Secretary, which is coordinating the Department's long-term care activities.

MEDICAID

Medicaid may reimburse for Adult Day Health Care Services in one of two ways: first, as outpatient hospital services, where the provider is licensed and certified as a hospital, and second as clinic services where the providers can be any licensed and certified health facility. There are over 100 day care programs currently receiving Medicaid funds—more than a two fold increase in the last 2 years. Some of these are funded under title XX as well. California, Massachusetts, New Jersey, New York and the State of Washington have been particularly active in this area. Maryland has recently passed legislation and developed regulations to provide Adult Day Health Care as a Medicaid service. In addition, we have a demonstration program, the Alternative Health Services Project operating in two health districts in the State of Georgia. Adult Day Rehabilitation is a major service in this program. We anticipate that programs will be added soon in Texas and Kansas.

Health Care financing Administration personnel offer technical assistance to States that are interested in providing Adult Day Health Care under Medicaid. We recently visited Kansas, Texas and Hawaii. A trip is scheduled to Florida next week.

MEDICARE

Medicare is designed to deal with the problems of financing short-term acute care and treatment for the elderly and disabled. For this reason, Medicare cannot pay for all of the services provided in Adult Day Health Care centers, except under demonstration conditions. For example, basic social services, transportation, meals and therapeutic recreational activities would not normally be covered by Medicare in an outpatient setting. Of course, Medicare will pay for health care services such as physical therapy, that are usually covered, if they are rendered by providers participating in Medicare.

DEMONSTRATION PROJECTS

In 1972, the Department initiated four demonstration programs under the auspices of the Administration on Aging and the Medical Services Administration which, at the time, administered the Medicaid program. In 1974, HEW contracted for a state of the art paper on Adult Day Health Care. At that time, approximately 15 programs were identified and approximately 10 were described in detail.

More recently, the Health Care Financing Administration has funded a variety of demonstration projects studying the problems in long-term care. We are also cooperating closely with the Assistant Secretary for Planning and Evaluation on the channeling demonstrations which are designed to assess the capacity of locally-based organizations to manage, coordinate, and arrange the provision of home delivered services, other ambulatory care services, and institutional outpatient services. Adult Day Health Care may be one of the services included in the channeling demonstrations. A revised notice of intent to initiate the National Channeling Agency Demonstrations program was published in the FEDERAL REGISTER on March 21, 1980.

SUMMARY

In summary, we feel that Adult Day Health Care Services can be an important health service as an alternative to institutional services. However, as you know, our programs are confronted more and more with budget constraints.

In spite of our budget constraints, we believe that we should continue to examine this most important service for the elderly, and should continue to look at it as part of a comprehensive coordinated set of services which provide elderly persons and their physicians options for receiving care appropriate to their needs.

Since the development of the four Federally funded projects in 1972, we have now over 100 Adult Day Health Care Programs operating with Medicaid reimbursement.

A directory of both Adult Day Health and Day Social Care Programs, listing more than 600 programs that provide services each day to almost 12,000 people, is scheduled to be published by HCFA this summer. A National Adult Day Care Conference was supported through a conference grant by the National Center for Health Service Research. The final report was completed under the direction of the Health Care Financing Administration. This conference served as a catalyst to form a National Institute on Adult Day Care under the auspices of the National Council on Aging.

We will continue to carry out demonstration and evaluation projects which focus on both health and social problems of the elderly and to provide technical assistance to States that express an interest in Adult Day Health Services.

Mr. Chairman and members of the committee, I would be pleased to respond to any questions that you may have.

STATEMENT OF JEFFREY C. MERRILL, DIRECTOR, OFFICE OF LEGISLATION AND POLICY, HEALTH CARE FINANCING ADMINISTRATION

Mr. **Merrill.** I just wanted to mention a couple of things about the Health Care Financing Administration's—HCFA—role in Adult Day Health Care Services, and talk about what we see in terms of the future.

First of all, I want to clarify a couple of things about the coverage under existing HCFA programs, and some of the funding for research and demonstrations.

As you know, both the medicare and medicaid programs are entitlement programs. As long as people receive services covered under the programs, and they are eligible, we will pay for those services.

Under the medicaid program we both encourage and support States in their efforts to establish Adult Day Health Care programs. Presently, we have programs in seven States, and some of those States are represented here today. In addition, we are in the process of starting programs in a couple of other States, namely Kansas and Texas.

Under medicaid, it is not mandatory to provide Adult Day Health Care Services. It is something that the State has at its option, and, as I said, some States have chosen to do this. We stand ready to help with technical assistance, or any other kind of assistance, to other States that are interested in providing this service.

Under the medicare program, we are constrained much more by statutory requirements. Medicare is designed to deal with the problems of financing short term acute care and treatment for the elderly and disabled. The long-term care benefit under medicare is very limited. There are some skilled nursing facility services provided, but this type of care is limited to 100 days in a benefit period. There are also home health services provided, with a limitation on the number of visits, but no intermediate care, and no Adult Day Health Care.

The only way that we can provide these services under medicare is through our research and demonstrations efforts. A number of these have been discussed already. Under these demonstrations, we can provide certain waivers which will allow the coverage of services that are not currently covered under the medicare program. The only exception, under medicare, where we cover something similar to this would be in terms of day hospitalization, or partial hospitalization programs for the mentally ill. Essentially in those programs, we consider day care as an outpatient service, and pay for most of the services that would be considered part of an Adult Day Health Care program.

We agree very strongly with many of the comments that have been made, and I appreciated Mr. Bram's recent comments that we have a lot to learn yet. We are working under very tight budget constraints, as you mentioned before, Mr. Chairman, and before we extend or expand services we feel we have to have a fairly good idea of what the implications of these services are going to be in terms of overall cost and cost effectiveness. In that light, we have embarked over the last 8 years on fairly extensive research and demonstration projects. In 1972, the Department initiated four demonstrations under the auspices of the Administration on Aging and the medicaid program. In 1974, we expanded these demonstrations to a number of other sites authorized under section 222 of Public Law 92-603. Right now we are not focusing on individual projects as much.

Mr. **Bonker**. You were given authority under what law?

Mr. **Merrill**. Under Public Law 92-603.

Mr. **Bonker**. To expand?

Mr. **Merrill**. To do demonstrations under the medicare program.

Mr. **Bonker**. Specifically for day care centers, or just in general?

Mr. **Merrill**. No, no, in general. It was an expansion of existing authority, but it allowed us to get into the area of Adult Day Health Care.

Mr. **Bonker**. What are some of the other demonstration programs under that authority?

Mr. **Merrill**. We have a number of demonstration projects in prospective reimbursement. For instance, in your State we are funding experiments involving alternative systems for hospital reimbursement.

Mr. **Bonker**. But in terms of alternative services.

Mr. **Merrill**. We have a number of channeling programs that are on going. That is what I was just about to mention.

Mr. **Bonker**. OK.

Mr. **Merrill**. What we are interested in looking at is the continuum of care in terms of long-term care services, whether it be institutional or community-base services. What we want to look at particularly are community base models which provide for case management in the channeling and assessment in referral of services so that a person who enters that system can get the appropriate services from the appropriate provider. Under our demonstration authorities we are now testing that out in a number of sites.

Our focus is not simply looking at one of these services, but the whole continuum of services, and providing models for the total set of long-term care services. On Lok is one of the projects that is covered under those demonstrations.

Mr. **Bonker**. I rather imagine you are interested in cost effectiveness of the programs.

Mr. **Merrill**. Absolutely.

Mr. **Bonker**. What do you have to say about the cost effectiveness of adult care centers, especially in light of Dr. Weissert's testimony?

Mr. **Merrill**. Well, some of the demonstrations are going on right now and it is a little premature to determine that. Our feeling is that there is no one of these services that is in every case more or less expensive than others. I believe that variable circumstances, such as an individual's level of disability, the support services that might be available, other than health services, and whether he needs homemaker services, will greatly influence the cost of an individual service for that person. Therefore, to say that Adult Day Health Care is universally less expensive than institutional care, or universally more expensive, or less expensive than home health services, would very much depend upon the individual.

Mr. Bonker. But that does not really help us as legislators who are trying to make good decisions on scarce Federal dollars as they relate to these programs. We have to have some idea of the cost effectiveness of these programs, especially if we are introducing alternative concepts. We are not going to have many Federal dollars to appropriate, and should we take away from nursing home care, and from some of these others for the clinics? I mean, if you cannot provide us with the basis of information so that we can make prudent decisions, I am not sure we are going to be effective at all.

Mr. Merrill. What I am saying is that—I agree with you.

The demonstrations that are under way right now, and the demonstrations that have been in existence for a long time are starting to provide us some data. What I am saying is that on adding Adult Day Health Care as an additional service under medicare, for instance, we believe in many ways it would be a very valuable thing to do. On the other hand, before we come up here and suggest legislation to the Congress, we would like to see under what circumstances and under what kind of system, and under what kind of reimbursement mechanisms it would be most helpful, and most cost effective to provide that service.

Mr. Bonker. So then, until you have that information, you would not recommend that we would expand funding for these programs.

Mr. Merrill. Under medicaid, where the program is a covered service if the State decides to exercise that option, we are working with the States to do that. Hopefully, with our technical assistance, we are helping them to develop a mechanism that is cost effective. Under the medicare program, I think right now we are reluctant to recommend that that service be covered.

Mr. Bonker. Well, Mr. Reed said that he was concerned about the rigidity, and the limitations on medicaid funding for this purpose. So obviously, you are moving cautiously. If you were more generous with the use of medicaid funds for adult care centers, he would not be complaining as he is.

Mr. Merrill. I think Mr. Reed's problems are specifically related to some difficulties between HCFA, and the State of Washington. Today was the first I had heard of that problem. I plan to go back to find out and try to get back with some response to Mr. Reed. I gather that is a unique problem, and it might have to do with some early decisions, not current thinking.

Mr. Bonker. Does that conclude your opening statement?

Mr. Merrill. The only other thing I want to say, and I think this refers to the other two individuals here with me, is that the Department, in general, is very concerned about the whole area of

Adult Day Health Care, and the whole area of long-term care services, both the health care portion of it, and the social services. As a result the Under Secretary has formed a task force on long-term care to try to look into these various issues, and to advise on long-term care policy issues within the Department. One of the first steps is that all the long-term care research and demonstration projects will be coordinated by the Assistant Secretary for Planning and Evaluation, which means that they can serve as the focal point for developing policy in cooperation with other agencies within HEW.

Mr. **Bonker**. Well, that may be in part an answer to the question staff had prepared, and that concerns HFCA technical assistance to States that are interested in these programs. Apparently we have been unable to identify a particular person within your agency with responsibility for day care, so I guess the question is twofold: one, who provides this technical assistance; and two, does such a person exist?

Mr. **Merrill**. Somebody within the whole organization—the whole organization being HEW, or Health and Human Services it is soon to be called—I do not think that person exists, very frankly.

Mr. **Bonker**. No wonder Mr. Reed is having problems.

Mr. **Merrill**. Within HCFA, I think that there is also a lack of coordination, very frankly. Up until 2 years ago, there were two separate programs, the medicare program, and the medicaid program. They were in two different agencies within HEW. It is a major step to bring them together to start that coordination.

Mr. **Bonker**. Well, I think what this points to is an example of how the agencies, through these demonstration grants, have entered a whole new field, and have developed a constituency, if you will, and a program that is without direct congressional approval, or authorization, or direction. Most of the time Congress will enact legislation to identify and fund programs. In this instance, there is no legislative basis for an adult care program, to exist. So obviously, in your department, you have not set up such an office; and since there seems to be a kind of frantic shopping around for available funds, Federal and State, to support these programs, it is being drawn upon from several sources, including your agency. Therefore, there is not a single person, or a single program involved. I really think it would be advisable before you move further, or expand to any greater degree the program, to wait for some congressional action so you have more direction, and more of an authentic means to carry on the administration of such a program.

Mr. **Merrill**. There is one other factor in terms of limited coordination I just want to mention. First of all, the programs are authorized under different statutory provisions. You are absolutely correct in saying there is no explicit enabling legislation under medicare, or medicaid in this area; but besides that, I think it is very important that many of these programs work through States, and that the agency within the State that handles the coordination is very different for programs under title XX, or under title XIX, or under title III of the Older Americans Act. So it is not only in terms of the Federal coordination, but I think the statute, and also the State's roles make it difficult to coordinate.

Mr. Bonker. OK, thank you, Mr. Merrill.

And now, we hear from our second witness. Is it Mike Suzuki?

Mr. Suzuki. Mike is fine.

Mr. Bonker. That is easier than the first one; Acting Commissioner.

Do I understand that they have abolished your office?

Mr. Suzuki. We are planning a restructuring of the Office of Human Services. The Administration for Public Services is one of the five current administrations in HDS which administers the title XX program. We are having a series of meetings right now with central office, and regional staff, relative to the proposed restructuring.

The function carried out by the Administration for Public Services will be continued by the Office of the Assistant Secretary, Human Development Services.

Mr. Bonker. It is safe to say you work somewhere in HEW.

Mr. Suzuki. I did when I left.

Mr. Bonker. Well, you have 5 minutes, and you may want to comment on your own personal survival, or the subject at hand.

[The prepared statement of Mr. Suzuki follows:]

Prepared Statement of Michio Suzuki, Acting Commissioner, Administration for Public Services, Department of Health, Education, and Welfare

Mr. Chairman and members of the committee, I am Michio Suzuki, acting commissioner for the administration for public services; and I appreciate this opportunity to speak to you today. States are permitted under the title XX legislation to determine what services they will offer to their eligible recipients. Adult day care services are offered by 38 states. Under title XX, adult day care services are defined as those social services which are provided in a protective setting for a portion of a 24-hour day to promote social, physical and emotional well being. However, title XX prohibits payment of medical services unless the medical component is an integral but subordinate part of adult care. Therefore, medical services are not generally offered as part of title XX adult day care programs.

The title XX annual report to the congress for 1979, indicates that the average number of individuals provided adult day care services per quarter, by states, was 36,671. The total cost of all recipients served was $54,203,581. It is estimated that expenditures for adult day care rose by $8.4 million in fiscal year 1979 over fiscal year 1978. Of the total number served, 39 percent are SSI recipients; 53 percent are income eligibles (that is, those with income below 115 percent of the median income of a family of 4 adjusted for family size). Adult day care services are not provided to individuals without regard to income. It is worth noting that although SSI recipients receiving adult day care services make up 39 percent of the caseload they represent 45 percent of the costs.

The range of activities provided by states in their adult day care services programs include group recreational activities, such as crafts of various sorts, in addition to group therapy sessions to deal with problems associated with the later years such as retirement, bereavement, handling stress and anxiety in widowhood and depression. These services also include assistance in maintaining a nutrition and health maintenance regime; counselling on personal and family relationships, and activities to help adult with impairments (strokes, recent heart attacks, etc.) to face the necessity of physical medicine and rehabilitation.

Adult day care services in the title XX program, offers an alternative to, or prevention of, institutionalization for physically or mentally impaired adults. Such services are provided in the form of supervision in a protective community setting for a portion of a 24-hour day.

Adult day care services are not within the adult protective services system. However, day care may be one of the services in the protective system. Day care should not be confused with those service mixes which are mustered to help an individual remain in his own home such as homemaker services, chore services or home delivered meals. Nor should day care be confused with adult foster care services which provide a protective placement for one or several older people with a caretaker over a 24 hour period of time.

The value of adult day care lies in providing social services over a period of less than 24 hours in a setting away from an individual's own home where that person can obtain meals, have a nap, participate in such recreational activities as they may wish, and mix and mingle with their peers as they wish.

For fiscal year 1979, eleven states planned to charge fees for provision of adult day care services. These states were: Connecticut, Minnesota, Mississippi, North Carolina, North Dakota, Ohio, Oklahoma, Tennessee, Utah, West Virginia, and Wisconsin.

Current information on specific auspices under which adult protective services are provided is scanty. Adult day care services are provided through senior citizen's centers, as part of the program in homes for the aged under sectarian auspices, or under other voluntary or "for-profit" agency auspices and in other ways.

In at least one center we know of, the Knowles Center, a 25 year old facility, in Nashville, Tenn., adult day care is provided as one of the services programs. Other similar centers provide an opportunity for socialization, rest and recreation for adults. Most participants are at least ambulatory although some centers that are barrier free do accept clients that are wheelchair bound.

Currently, states faced with financial stringencies may be considering reducing their programs, including adult day care services. There are, as yet, no precise data available. States CASPs for fiscal year 1981 due on October 1, 1980 will provide the first clues as to states intentions.

STATEMENT OF MICHIO SUZUKI, ACTING COMMISSIONER, ADMINISTRATION FOR PUBLIC SERVICES, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. SUZUKI. I appreciate the opportunity. I will not read the statement which we are submitting on behalf of OHDS, and also for Administration for Public Services, but only highlight the significant portions in view of time limits. Title XX of the Social Security Act is the newest of the Social Security Grant In Aid Programs. It provides for grants to States for social services. In order to get a perspective, in fiscal year 1979, 2.9 billion Federal dollars was allocated to States for social services. In the current fiscal year, because of a lapsing of legislative statutory authority, that funding is reduced to $2.5 billion, although both houses have passed bill H.R. 3434, which would raise the ceiling back to $2.7 billion.

What I will try to convey is really what is happening relative to adult day care services in the context of title XX. Title XX funds are allocated to States on the basis of population, and it really is not a grant that is given ahead of time. It reimburses States for expenditures for services which the State is free to select. States are not required to offer any specific service, nor are they required to serve any particular target group. Except for the fact that there is a 50-percent rule which says a significant amount of the title XX resources must be offered to welfare recipients, the law also provides that at least three services must be aimed at the SSI supplementary security income recipients. States do not have to offer any specific service, so that they are free to select a range of services they wish to provide. Of the 51 jurisdictions, that is, the 50 States, and the District of Columbia, 38 States offer adult day care services. States define the service. We have examined the plans of the 51 jurisdictions. Adult day care is defined as those social services, which are provided in a protective setting for a portion of a 24-hour day to promote social, physical, and emotional well being.

Title XX is not a grant mechanism for the funding of medical care. In some instances you can provide certain medical services when they are integral but subordinate to a social service, so that in terms of a model we tend to think of title XX adult day care as perhaps fitting into the social model, as it was called this morning.

Mr. **Bonker**. Now, that is pretty interesting, if not revealing. If you are concerned about title XX money that is intended for social services being used for health care, then how do you respond to what are obvious examples of this money being used directly for health related programs?

Mr. **Suzuki**. Again, if title XX funds are used specifically for medical or remedial care health programs, it is fundable only if it meets the specific condition that you have a socially focused adult day care program, and the medical care provided is an integral part of the social service.

Mr. **Bonker**. That is not what I am hearing. What I am hearing is that it is basically a health care program with some of the social benefits inherent in it.

Mr. **Suzuki**. That may be another model under the medicaid program, because medicaid and medicare are really health financing mechanisms.

Mr. **Bonker**. That is right.

Mr. **Suzuki**. If title XX funds are used that way, they are subject to audit. In other words, in some places where you have essentially a medical health program, unless it really is a part of a larger social services program, that funding is questionable.

Mr. **Bonker**. OK. Well, let me ask you then, Mr. Suzuki, in Washington State, the budget for adult day care is $982,000, and here is the breakdown from a State sponsored program, the Senior Citizen Services Act, $517,000; title XX, $162,462; day treatment, $8,721; title XIX, $152,019; client match for this other State program, $98,280; private, $43,752.

Now, that represents the funding sources, of which title XX is prominently represented. Now, how do you know whether this is for basically medical, or health-related programs?

Mr. **Suzuki**. Again, let me point out—I cannot speak to this particular example. You know, I have not looked at Washington specifically. I heard about it this morning. But again, take a situation where you have multiple funding. I cannot speak to this Washington State example specifically, but even in a health focused program it is possible under title XX for selected social services, including adult day care to be funded with the XX money, and other health-related activities perhaps funded out of other mechanisms. I do not know, and I will be pleased to examine and have our staff review the Washington example. But by and large we have the same issue—can I give you the illustration in another somewhat related field?

You have homemaker services funded out of title XX, and you have home health aid funded out of health financing mechanisms. Now, at the extremes you can make a pretty clear picture that there is no a medical or remedial service on the homemaker side, and way over here it is very clear that this person is really getting a medical treatment as a part of home health aid service. I would concede that as you get into the middle area, gray area, it is tough at times to make the call as to whether one that is really a health financed activity, should be properly on that side of the ledger, or a social service activity. But by and large, in terms of the review that we make, and we are constantly reviewing the contracts and the programs that we fund, our law says that we cannot fund medical care. We have disallowances that run in the millions of dollars in a year, relative to the kinds of things we fund. I hope this is not a violation of our rules and regulations, but we arel certainly prepared to look at the Washington model.

Now, let me just say this, that while in the context of title XX, adult day care service is not a large portion, it does not even achieve 2 percent of our funding; but in terms of dollars, for fiscal year 1979 out of title XX, we spent over $54 million for adult day care programs out of title XX in the 1951 jurisdictions. It is less than 2 percent, but it is the fastest growing single service proportionately in the title XX program. Between fiscal year 1978 and 1979, title XX expenditures for adult day care services increased by almost $8.4 million; almost by a quarter, so it is not a major piece by any means, but certainly a significant piece.

Mr. **Bonker**. Well, what I am hearing is this, that based on testimony from earlier witnesses, that when we talk about adult day care we are talking primarily about health care, health-related care. This is the testimony that came from Ms. Klapfish, and Mr. Reed. When I try to make a distinction between the two models, she said it was very difficult because they are kind of mixed; but basically it was health related.

Now, I am hearing from you that $54 million goes to help support these programs, but according to your policy, or regulation——

Mr. **Suzuki**. By law.

Mr. **Bonker**. It is questionable whether these funds ought to be used to fund programs that are health related.

Mr. **Suzuki**. Health related is OK. In other words, they can be health related, but I am saying basically medical, or remedial health programs are not fundable under title XX.

Mr. **Bonker**. Then based on the testimony I have heard today, I would have to say that those programs probably are in violation of the law which restricts your funding for adult care centers. It also seems to me that there is some shopping around for other Federal programs that can underwrite adult day care centers. That is why there is a lot of pressure now for medicaid and medicare money. It seems to me it is a prime example of what happens if the agencies take on a new dimension without proper congressional authority for either the program, or the funding; and we are heading toward real confusion, and possible violations of law until we can somehow bring more coherency and statutory approval to adult day care centers.

Mr. **Suzuki**. I understand the point you are making. I would just make two comments. One is that neither the Federal law, nor the Federal bureaucracy requires any specific service to be provided in States. It does not require adult day care be provided in States, not——

Mr. **Bonker**. I understand. You made that point.

Mr. **Suzuki**. Also it really is up to State option. It is this point I felt that I wanted to share with you that when 51 plans came in at the beginning of title XX in 1975, we had, I think 1,313 different services named under title XX. It is out of that wide range—many of them were called different things—that States defined their services. There are now probably about 50 different social services that are funded in States across the country, and I just wanted to point out that out of that major group there are a number of those like adult day care that States are selecting to spend additional funds on.

The other point that some of my colleagues are pointing out to me, and I think it is a point that should be mentioned, is that in terms of title XX a significant population needing this service is the mentally retarded, and mentally handicapped population. There again, it is up to the State as to how they wish to target the adult day care that they offer. It is up to senior citizen centers, which target group they want to direct their adult day care programs toward. But again, I just share what is happening in the context of title XX. In terms of the choice though, and although we have not had 1980 data relative to 1979 on adult day care, there seems to be an increasing growth in this service although it is a small one within the larger social service program under title XX.

Mr. BONKER. But it is growing all the time.

Mr. SUZUKI. It is growing.

Mr. BONKER. I think that it would be a good idea if you would submit to the committee the statute which prohibits, or restricts your contributions to programs that are exclusively, or predominately for health activities.

Mr. SUZUKI. Certainly, title XX statute.

Mr. BONKER. And also your analysis as to how they relate to your funding of adult day care centers.

[The following information was subsequently received from Mr. Suzuki:]

1. Describe the statute which prohibits or restricts your contributions to programs that are exclusively, or predominantly for health activities. (Line 3502.)

Answer. Title XX, Section 2002 (a)(7)

"(7) No payment may be made under this section to any state with respect to any expenditure

(A) for the provision of medical or any other remedial care, other than family planning services, unless it is an integral but subordinate part of a service described in paragraph (1) of this subsection and Federal financial participation with respect to the expenditure is not available under the plan of the State approved under title XX;"

2. And, also, your analysis as to how they relate to your funding of adult day care centers.

Answer. See Report from Committee on Ways and Means of the House Report No. 93-1490, 93rd Congress, 2nd Session, dated Nov. 22, 1974, Page 7, which identifies a list of prohibited activities, among them funding of medical services.

This report covers the Bill which later became title XX. The report points out that funding medical services, with the exception of family planning services and of integral and subordinate medical aspects of a service directed at one of the five goals, is prohibited.

The Bill specifically prohibits social service funds to be used for medical services for which the individual has Medicare coverage or which are available under the Medicaid plan. This provision is intended to avoid the dispersion of funds destined for social services to other service programs for which other sources of funding is more appropriate.

Specifically, the provision precludes States from claiming reimbursement under social services, which has a 75 percent Federal match, for services more appropriately covered under title XIX, which, for many States, the matching rate is less favorable.

2. (Would you submit) your analysis as to how they relate to your funding of adult day care centers. (Line 3507-8.)

Analysis. Adult Day Care Services, provided in a health facility under the direction of a physician where the service is medically prescribed, would be considered a health activity and would not be eligible for title XX funding. (Medical model.)

Adult Day Care Services, funded by title XX, as a social service, may be provided at a free standing Adult Day Care Center, or a Senior Center. Since participants in an Adult Day Care Services program are at risk because of some impairment in functioning, the adult day care services are provided in a protective setting, under supervision for a portion of a 24-hour day. (See M.S. testimony, Page 2, Paragraph 2, 2nd sentence.) The focus of activities are directed towards promoting the social, physical and emotional well-being of the participants. (Social model.) Any medical or remedial care which might be provided as part of Adult Day Care Services in the social model can only be funded when such medical or remedial care are evidently an integral but subordinate part of the social service program.

Mr. **Bonker.** I hate to move on to the next witness because this information is so important, but I am under some time restraints, and we will have to adjourn the Committee in a few minutes, so I would like to move now to the third witness on the panel, Kathryn Morrison, who is the Deputy Commissioner on Aging. That office is still in effect, I assume.

Ms. **Morrison.** Yes, it is.

Mr. **Bonker.** OK, Administration on Aging, with the Department of Health and Human Services.

You can be the anchor person. You can have the last word today.

[The prepared statement of Ms. Morrison follows:]

PREPARED STATEMENT OF KATHRYN MORRISON, FOR ROBERT BENEDICT, COMMISSIONER, ADMINISTRATION ON AGING, HUMAN DEVELOPMENT SERVICES

Mr. Chairman, and committee members, I am Kathryn Morrison, Deputy Commissioner for the Administration on Aging, and I am pleased to resond to your invitation to discuss adult day care on behalf of Commissioner Robert Benedict. Adult day care is well recognized as a service that can prevent, shorten, or delay the need for institutional care or expand care choices available to families.

The AOA support adult day care in several ways. Under the Older Americans Act, it provides title III-B funds for support of adult day care services. It provides funds for the operation of senior centers in which many adult day care programs are located. In some instances, adult day care residents participate in congregate nutrition programs.

Currently, 45 States report that they have adult day care funded either through title XIX or title XX or title III dollars. Of these, 19 States report using title III dollars. For example, there are 69 day care centers supported by title III in the States represented by members of this subcommittee. Thirty-four of those are in senior centers.

Mr. Chairman, I would like to report on some of the more important and innovative projects that the AOA has supported. Let me describe for you, an example where title III funds (together with other Federal resources) are playing a significant role in assisting day care. In Dade County, Florida, there are currently seven day care centers, four of which are sponsored by the Dade County elderly services division and use titile III funds. These four centers serve 270 clients a month.

Of the older persons who receive such services, 90 percent are at or below the poverty level. In some cases, older persons volunteer in each of these centers to help those who are less able. Families are involved as volunteers as well. Each center provides hot meals, transportation services, health screening and education, and family counseling. When an individual condition improves enough, the elderly service division has a special assistance effort entitled the "impact program." Under this program, if an individual declines in his or her physical condition, the elderly service division provides for home visits. This is an example where title III funds provide an important care choice for older persons and their families.

The AOA has invested $4.2 million in model day care projects between 1972 and 1980. These model projects cover a range of day care concerns. Let me cite just a few: The Burke rehabilitation center project, a day hospital, was funded to determine the reasonableness of a day hospital as a means of providing rehabilitative services for the chronically ill or the physically disabled older adults. This demonstration has shown the value of this setting in encouraging participants to renew their interest in themselves and others, by group activities which require interpersonal communication.

A grant awarded to Case Western Reserve University in Cleveland, Ohio, focused on both physically and mentally impaired older persons. This project not only provided services to the frail elderly, but also to the family and to older volunteers to active mutual help.

The On Lok Senior Health Services program in San Francisco, California, is a pioneer in the field of adult day care designed to adapt to the ethnic and cultural backgrounds of Filipino, Chinese, and Italian older persons.

A Lockport, New York, project demonstrated the feasiblity of integrating severly and moderately impaired older person within the structure of a multipurpose senior center program. A project in Wichita, Kansas, has shown that adult day care services can be provided in rural areas, by using an existing nursing home. Public and private replication of these models has contributed to the growth from 15 programs nationally in 1974 to an estimated 600 in 1980.

There remain a number of questions about the provision of day care, including issues of funding, cost of services, and variety of service models and the mix of services. The AOA is currently investing research dollars in identifying answers to some of these problems. For example, we will receive in the next few months an assessment of the cost of alternative levels of care, and a comparison of benefits received in day care centers, day hospitals, nursing homes, and domiciliary care arrangements.

Additionally, AOA provides funds for training service providers and State and area agencies personnel involved with providing adult day care.

The 1978 amendments contains a new provision, section 422, special projects in comprehensive long term care. The AOA together with the health care financing administration is launching a major demonstration program this year which will include adult day care as an important service element.

Mr. Chairman, this concludes my prepared remarks. I would be happy to answer any questions you may have.

STATEMENT OF KATHRYN M. MORRISON, DEPUTY COMMISSIONER, ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Ms. MORRISON. Thank you very much, Mr. Chairman.

I would like to just summarize very quickly some comments about the program within AoA.

Under title III of our law, money is distributed in States to area agencies which have a wide latitude in the kind of programs they choose. They may choose to have a day care program, or to provide partial funding for such a program. In fact, 19 States chose to do that. In most of these cases we are talking about partial funding, or the initial funding for such a program. Whereas the gentleman on my right is speaking billions of dollars, we speak in millions of dollars at the Administration on Aging. However, we are flexible on money. We have fewer restrictions in terms of the kinds of services that we can provide, and fewer limitations on the population eligible than either XIX or XX.

We have, over the last several years, also funded a number of demonstrations. About $4 million worth of demonstrations with the discretionary money that we have available to us. I would just like to mention a few of them quickly, because I think they illustrate some things that you were commenting on before. We did provide, and still do provide some of the money for On Lok. This is a separate facility for day care, and it now provides a continuum of care. We have provided money for Lok Port, a day care service located in senior centers. They found that it was necessary to increase their senior center staffs substantially so they could provide the services that were necessary for this kind of a function.

We also, right now we are funding a project in Wichita, located in a nursing home. So again, it is making use of the facility that is there, putting another kind of service in it.

Here, I would just like to mention something that I learned while I was in Wisconsin and sat on a committee that determined medicaid rates. When we went through the process of calculating the rates, we would assign a specific amount of time per person per day for occupational therapy or other services. A fee was associated with each. This approach was used to build the cost, so that if you were to introduce a new group of people and services into that facility, it would be necessary to pay extra for the staff. Because of physical facilities, and because of location, particularly in rural areas, it might be a very wise place to locate day care services, in nursing homes and senior centers, but it will not be done without additional resources.

We are in the process now of doing some research to find out the differential of costs in the various sorts of care: care in nursing homes, care in domicilliary homes, care in day care, and in-home care, so that we can begin to add to the kind of information that Mr. Weissert has, and begin to develop a body of information about the cost.

We are also associated with HCFA in the demonstrations on long-term care. Originally we had 10 million, I guess we are down to 7.5 million now, to donate to that effort, and you have 8, I believe.

Mr. **Merrill**. We are down, too.

Ms. **Morrison**. Part of the demonstration will be with regard to day care. It involves the whole continuum of care, one of the parts of which is day care. Out of that demonstration will come some information about the various kinds of costs.

I guess I would just like to say that our States, and our agencies have found it worthwhile to fund day care. They do have the choice of whether or not to do it. It is an allowed service, it is not a mandated service. They have found it wise to do that.

We have had several demonstrations which no longer receive AOA funding. They still are funded. They are still continuing. They are part of the group, I think you could properly say are scrambling for title XX and title XIX funding, but they still have managed to exist.

We are also involved in more demonstrations with regard to the whole continuum of care. We see this as a valid part of that continuum.

Thank you.

Mr. **Bonker**. Thank you, and I would like to thank each of you for excellent testimony this afternoon. I am sorry more of my colleagues are not here because it is an important subject, and the record will be held open for a few additional days if you want to respond to some of the comments or questions that have been raised here.

I may ask the chairman to conduct another afternoon of hearings, at least so we can hear from the administration witnesses, because I think the program has reached a stage where we are either going to expand it and authorize greater levels of funding, or we are not. If it is a valid program worth our attention, and it is competitive with other programs, then I think Congress ought to express itself accordingly, but I do not think that the agencies ought to move much beyond where they are until Congress has spoken on the matter.

Thank you, once again for coming, and to the audience for your patience for the various chairmen, and the interruptions that we have had today.

The subcommittee will stand adjourned.

[Whereupon, the hearing was adjourned at 3:25 p.m.]

APPENDIX

April 23, 1980.

From: Joanne Jackson Yelenik.
To: Subcommittee on Health and Long-Term Care of the Committee on Aging.

Please accept along with a copy of my oral statement and enclosed written documents[1] a review of a book entitled, "Unloving Care," which explores the ineffectiveness of Nursing Home Care facilities, and the extent to which this kind of care is forced upon families by governmental and medical systems. Also I am giving the Committee a copy of a law passed in January of this year by the State Legislature of California seeking to address and rectify the prejudices of financial aid and medical insurance systems as they affect sufferers of chronic brain damage related illnesses.

Thank you.

Impersonal Caretakers

(By Paul Starr)

Some problems in society exist for reasons beyond our conscious control; others are quite clearly of our own making. Before reading Bruce Vladeck's new study I would have put nursing homes in the former category. I would have thought that, at bottom, their shabby conditions, their impersonality, their routine indifference and isolation were the product of some inescapable currents in our society, such as the decline of the extended family, or the consequence of some deep-set patterns in our culture, such as the infatuation with youth and the horror of old age, or perhaps the result of some irremediable defect of the human soul that makes us deny death and shun the dying.

But, as Mr. Vladeck's study makes clear, the development of the nursing home industry was almost entirely the product of recent public policy. Nursing homes are not institutions that have been with us since time immemorial. Even two decades ago they were not nearly as widespread as they are today. As of 1963, there were about half a million nursing home beds; now, thanks to Medicare and Medicaid policies and the failure to develop adequate alternatives, there are a million and a quarter. At present rates, one of every five of us who lives past 65 will spend time in a nursing home—many needlessly, and at huge expense to society. As of 1977, Mr. Vladeck reports, we were spending more than $12 billion a year on nursing homes. In the absence of any major changes in policy, according to a Congressional Budget Office study, that figure will rise to $22 billion by 1985. And at the start of the next century, when the elderly dramatically increase as a proportion of the population, we will need still vastly greater sums to support what is, even at best, a form of impersonal caretaking universally regarded with dread.

The prospects are sobering. Yet rather than give us just another investigation of deplorable conditions in nursing homes, Mr. Vladeck—a political scientist by training and now an assistant commissioner of the New Jersey State Department of Health—has chosen to address the sources of failure and the possibilities for change by exploring the history and politics of the nursing home industry. The result is an analysis more powerful in its impact and more profound in its implications than a muckraking exposé. For what is at issue here is not the callous greed of a few unscrupulous speculators, but rather the failure of government to deal intelligently with a problem of broad human and financial dimensions or to care decently for weak and defenseless people.

Mr. Vladeck, however, is not among those who attribute government failure to the natural incompetence of public officials, so often contrasted with the presumed genius of private management and the wonders of the free market. Nor does he ascribe failure merely to the predominance of proprietary, as opposed to nonprofit, facilities, although he acknowledges that the proprietary homes have been the source of the worst abuses. The picture is far more complex. What emerges in

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[1] The 11-point suggestions for legislation is found in the March 16, 1980 letter to Congressman Michael Barnes enclosed herein.

"Unloving Care" is a devastating critique of policies of rational cost minimization that have relied on the private sector to provide services and on government to correct deficiencies through incentives and regulations.

Nursing homes received their impetus in the 1960's partly from the false belief that moving patients out of hospitals into less expensive nursing facilities would reduce the costs of hospitalization. (In fact, longer institutionalization in nursing homes offsets the savings from shorter hospital stays.) Subsequently, nursing homes themselves were divided into two classes ("skilled nursing facilities" and "intermediate care facilities"), supposedly corresponding to different levels and costs of care. But as Mr. Vladeck observes, the economies that such measures were supposed to yield by matching services to needs never materialized, except perhaps from the fact that transferring old and frail people from one institution to another tends to kill them off at a higher rate. Policy makers, chasing after illusory efficiencies, were oblivious to the real human misery their reforms were causing.

Perhaps none of their illusions have been more powerful than what might be called "the mythology of incentives." Instead of providing services directly, government in recent years has more often contracted with profit-making firms and relied on systems of incentives to maintain quality and control costs. It is not an exaggeration to suggest that this faith in private action and the effectiveness of incentives, which Charles Schultze several years ago called "the public use of private interests," is now the dominant ideology of American public policy.

In the case of nursing homes, the problems with this approach should have been evident from the outset. It is difficult, if not impossible, for government to measure the quality of the services it is buying, much less for the residents of nursing homes to act as informed consumers. Sometime the methods of reimbursement for nursing care were too complex and changed too often to produce the results expected of them. But often, private nursing home operatiors simply outwitted the system. The theory of incentives presumes that private entrepreneurs can be led about by their noses by cleverly designed incentives. What frequently happened, however, was that nursing home operators manipulated the reimbursement system and milked it for all it was worth.

Of course, some state governments did not even try to create incentives for high quality services through their methods of payment. In some states, Mr. Vladeck writes, nursing homes, like medieval armies, were basically given "subsistence plus all they could steal."

A further source of failure might be termed "the bias of regulation." As Mr. Vladeck points out, insofar as measurable "inputs" are important, regulation can effectively improve performance, but when the relevant "inputs" are less measurable, regulation doesn't work. Regulation works best when "engineering content" is high, so regulatory measures did succeed in accomplishing some objective, such as making nursing homes relatively fireproof. But regulation does not deal effectively with the human relationships that determine whether nursing homes are decent places to live.

Among the actions that Mr. Vladeck would take to improve nursing homes would be to require that they be open to outsiders, such as volunteers, who could exercise the vigilance that residents cannot exercise for themselves. And, recognizing that perhaps 50 percent of nursing home residents don't need to be there, Mr. Vladeck would, over time, close down half of the industry's capacity and use the resources to expand sheltered housing and home health services. (Sheltered housing, unlike nursing homes, allows residents to maintain their own apartments, but provides services and assistance nearby.) All these programs would be financed through community agencies with fixed budgets for long-term care, which would act as gatekeepers to prevent a run on the public treasury. The result would be to move the country toward the kind of home-based geriatric services that the British have developed.

Radical as these measures sound, they may not go deep enough. To shift from nursing homes to sheltered housing may turn out to be only another change in nomenclature, if no attempt is made to relieve the social isolation of the aged poor. Watching television in sheltered housing may be no better than watching television in nursing homes. Social policy has to concern itself increasingly with the social relations that sustain well-being; considerable evidence now suggests that the vitality of family and friendship networks has a dramatic effect on health. We need to find ways to strengthen those human relations, instead of relying on regulated entrepreneurs to provide substitutes for missing homes and moral communities.

ASSEMBLY BILL NO. 1043—CHAPTER 1058

An act to add an article heading immediately preceding Section 446 of and to add Article 2 (commencing with Section 447) to Part 1.95 of Division 1 of, the Health and Safety Code, relating to brain-damaged persons, and making an appropriation therefor.

[Approved by Governor, September 27, 1979. Filed with Secretary of State, September 28, 1979.]

LEGISLATIVE COUNSEL'S DIGEST

AB 1043 Agnos. Brain-damaged persons; pilot project.

Under existing law there are no programs that specifically provide services and financial assistance for brain-damaged persons.

This bill would require the Director of Mental Health to establish a one-year pilot project for such persons by contracting with an appropriate nonprofit community agency to conduct a program providing for diagnostic services, in-home support services, out-of-home services, and counseling and legal services.

The bill would require the director to use any available funds and would appropriate an additional $250,000 for such purposes.

The bill would also require the director to make a report to the Legislature on the pilot project, as specified.

Appropriation: yes.

The people of the State of California do enact as follows:

Section 1. An article heading is added immediately preceding Section 446 of the Health and Safety Code, to read:

Article 1. General Provisions

Sec. 2. Article 2 (commencing with section 447) is added to Part 1.95 of Division 1 of the Health and Safety Code, to read:

Article 2. Pilot Project for Brain-Damaged Persons

447. It has come to the attention of the Legislature that:

(a) State public policy discriminates against brain-damaged adults.

(b) Brain damage is often a long-term chronic illness, the costs of which are most often not covered by health insurance or existing government assistance programs.

(c) Financial assistance is not available until after families have struggled to care for family members and exhausted their own financial resources.

(d) If brain damage is diagnosed as a mental disorder, financial liability is significantly less onerous.

(e) Separable and less onerous financial liability already exists for programs serving the developmentally disabled and crippled children even though the medical and treatment needs may be identical to those of brain-damaged persons.

(f) The term brain damage is broad in scope and covers a wide range of organic and neurological disorders.

(g) Services required by brain-damaged persons often cross the service line of a number of different programs.

447.1. It is the intent of the Legislature to establish a pilot project to:

(a) Assist families in securing services, information, and counseling necessary for the care of brain-damaged family members.

(b) Coordinate funding and services among state departments and programs in order to provide an integrated program and single service access for persons with brain damage.

(c) Facilitate the integration of existing funds and services for persons with brain damage.

447.2. The Director of Mental Health, herein referred to as director, shall administer this article and establish such rules, regulations, and standards, as the director deems necessary in carrying out the provisions of this article.

447.3. The director shall establish a pilot project to be conducted by contract with an appropriate nonprofit community agency to integrate services and funds for persons with brain damage.

447.4. In choosing an appropriate nonprofit community agency to conduct the pilot project, the director shall give priority to the following:

(a) An agency which has previously provided information and support services to families of brain-damaged persons within a population area or county of at least 500,000 persons.

(b) An agency which includes family members of persons with brain damage on its governing board or advisory boards.

(c) An agency which has shown a capacity to address the needs of brain-damaged persons and their families.

447.5 The Agency conducting the pilot project shall provide the following services:

(a) In-home support services shall be provided by the pilot project through the establishment of a client voucher system. The voucher system should be available to family members, in lieu of cash assistance, to reimburse for a wide variety of in-home services, as specified in Sections 12300 and 14132 of the Welfare and Institutions Code, including but not limited to, the following:

(1) Nursing services.
(2) Housekeeping services.
(3) Home health services.
(4) Attendant care.
(5) Transportation.
(6) Respite care.

(b) If additional funding from sources other than the General Fund appropriation contained in the act by which this article is enacted become available, the pilot project under this article shall provide additional services in the following order of priority:

(1) Adult day health care services.
(2) Diagnostic services.
(3) Out-of-home 24-hour skilled nursing services.

(c) The pilot project shall provide legal, financial, and postdiagnostic family support counseling, information about services to persons with brain damage, and overall project administration. The pilot project may provide such services directly or by contract.

447.6. The director shall establish criteria for program eligibility for persons with brain damage, including financial liability pursuant to Section 447.7. The director shall assume coordination of existing funds and services for persons with brain damage, and for the purchase of in-home services through the client voucher system described in subdivision (b) of Section 447.5, with other departments that may serve persons with brain damage, including the Department of Rehabilitation, the State Department of Health Services, the State Department of Social Services, and the State Department of Developmental Services.

447.7. The parent, spouse, or child of a person receiving services under this article or the person receiving the services may be required to contribute to the cost of services depending upon their ability to pay, but not to exceed the actual cost thereof, as determined by the director.

447.8. In considering total funds available for the project, the director shall utilize funding available from appropriate state departments, including, but not limited to: the State Department of Health Services, the State Department of Social Services, and the Department of Rehabilitation. Funding for services not available from existing programs shall be provided from the appropriation contained in this article.

447.9. The pilot project under this article shall be limited to one year and the director shall evaluate the success of the pilot project. The director shall report such evaluation to the Legislature, not less than three months following the completion of the pilot project, and the findings of the evaluation shall address at least the following:

(a) Reduced need for institutionalized services by providing in-home support services.

(b) Number of persons in skilled nursing facilities who transfer to less dependent 24-hour care settings.

SEC. 3. The sum of two hundred fifty thousand dollars ($250,000) is hereby appropriated from the General Fund to the Director of Mental Health for expenditure during the 1979–80 and 1980–81 fiscal years for the purposes of Article 2 (commencing with Section 447) of Part 1.95 of Division 1 of the Health and Safety Code, provided that a sum not to exceed thirty thousand dollars ($30,000) of such amount shall be expended by the department for the adminstration of the pilot project established pursuant to Section 447.3 of the Health and Safety Code. Such funds are in addition to other available funds for services provided in such article.

PREPARED TESTIMONY OF JOANNE JACKSON YELENIK

The material enclosed chronicles some of the history of my family as it relates to the matter of the support and care of my father, Harry Jackson, through the period of the last two years of his seven long years suffering from Alzheimer's Disease.

I respectfully request that this material which includes the following information be included as part of my testimony before the Hearing of the Subcommittee on Health and Long Term Care:

Washington Post Article on Harry and Bessie Jackson, January 31, 1980, Maryland Section.

Letter of Legislative Recommendations to Congressman Michael Barnes, March 16, 1980.

Letter to Bessie Jackson from Congressman Claude Pepper, March 11, 1980.

Letter to Mr. Phil Donahue, March 16, 1980.

Letter to Ms. Dorothy Gilliam, Washington Post, December 21, 1979.

Letter to Medical and Social Service people working with the case.

Letter of a copy of correspondence of Jim MacRae of the Support Center, Inc., Wheaton, Maryland to Mr. Curtis Vanover of the Department of Social Services, Montgomery County, December 18, 1979.

Newsletter of Alzheimer's Association, Rockville, Md. Branch.

Newsletter of Alzheimer's Disease Association of Maryland Sponsored by the T. Rowe and Elanor Price Center for Dementia, The Johns Hopkins University School of Medicine, The Johns Hopkins Hospital.

I hope in the near future to submit additional material to the Committee relating to the care and treatment of Alzheimer's Disease and to the type of Social Service and Medical Care Services that are most needed.

Thank you for your attention.

BATTLING THE IRREVERSIBLE EFFECTS OF ALZHEIMER'S DISEASE

(By Janet Cooke)

When Harry Jackson was younger, he was a skilled electrician and craftsman who built and repaired a variety of machines. The work was both his livelihood and pleasure. He was, according to his family, convivial and gregarious.

Today, he is a fragile and silent man who sits quietly on the sofa and watches daytime television programs. A victim of Alzheimer's disease, he bears little resemblance to the person described by those who knew him in other days.

But Jackson remains an important part of his family, whose members are struggling to permit him to pass his remaining days with grace and dignity.

Alzheimer's disease is an irreversible and untreatable disorder that causes a gradual loss of intellectual and physical capabilities, according to Dr. Robert Butler of the National Institute on Aging. In its final stages, the patient may become unable to recognize anyone—including himself.

Alzheimer's is "one form of what was once called senility," said Butler, who added that while the disease is always fatal, death is almost never swift.

He estimates that nearly half the patients in nursing homes in the United States are victims of Alzheimer's.

And then there are the people like Harry Jackson, whose families want to care for them at home. Bessie Jackson, his wife of 40 years, and their daughter and son-in-law, Joanne and Ron Yelenik, say they did not consider any other alternative from the beginning of Jackson's illness. Although Mrs. Jackson and the Yeleniks do not regret their decision, they have discovered that it is a grueling one to live with.

Jackson, who is in his mid-70s, lost the ability to speak nearly six years ago, and must have help with nearly all routine, day-to-day activities.

Health care experts agree that home care is less costly than institutional care, but say there is little public aid available to families like the Jacksons who want to nurse sick and aging relatives at home.

"I am amazed," said Mrs. Jackson. "I could get all kinds of help if I wanted to put him away. But for the most logical thing here, for keeping him in familiar surroundings where he is loved, there is not a penny."

"I'm so angry," she continued. "You hear a lot of talk about keeping your loved ones at home, but basicially, I think that doctors, agencies, and goverments are very insensitive to the whole thing.

"When Harry began to be really ill, the first thing they would ask me was if I had made any plans. What they meant was, had I though about putting him in a nursing home. Listen, this is a man I've loved and lived with for 40 years, and I expect to do more for him than stuff him into the corner of some institution at the time when he needs me most."

Mrs. Jackson has sought help from the Montgomery County Department of Social Services, hoping for the aid of a homemaker for six or eight hours each day. Such help would free her for routine chores outside the home and for a partial return to a life of her own, she said. The department has provided a homemaker who helps out two hours a day on two days each week.

While her daughter Joanne says that Mrs. Jackson is "almost inordinately grateful for any help that she gets," the four hours a week are not enough. She lives an exhausting and sad life, watching her husband fade away, and passing the time without friends, without diversion, and without laughter.

"We knew a lot of people back in New York," said Mrs. Jackson, who moved to Rockville two years ago to be near her daughter. "I have met some very nice people here. But I can't go out, and, with a few exceptions, people can't come in. It's just too depressing for them."

Before a serious decline in his health last month, Jackson attended a day-care program for the elderly offered by Support Center Inc. in Silver Spring. He participated twice a week, for five hours at a time.

The director of Support Center, Jim MacRae, said he is very worried about Mrs. Jackson, because, "she needs all of the help that she can get. Most of the time, she's just exhausted." MacRae acknowledged that "there are only a limited number of services available," and said he believes the county Department of Social Services "is probably doing all that it can right now."

Jack Hiland, associate director of the department, said that a maximum of 20 hours of service weekly is "the best we could ever do" in a case such as the Jacksons'. He said a lack of manpower, rather than lack of funds, is the problem.

"It's ironic," said Hiland. "We're one of the wealthiest little communities around, and we still can't get it together to get the services."

The Jacksons live on a fixed income, and although they have managed to pay the staggering medical bills that have accumulated over the years, Mrs. Jackson said she cannot afford to hire someone to take care of her husband eight hours a day.

Nancy L. Mace, center coordinator of the Alzheimer's disease association of Maryland at Johns Hopkins University said that home support systems are underfunded even though they are significantly less expensive than the cost of care in institutions.

"Funding for home care of the sick and elderly is just not a politically attractive issue and there is not enough public recognition or awareness of the problem," she said.

Mace said some form of assistance is crucial for families who care for Alzheimer's victims at home because "some life of one's own is a serious issue here. Some of these people just never leave the house. In essence, they've really lost their partner, but the whole process of grieving has to be delayed, because although he's gone, he isn't dead."

The association, which was formed last fall, has four main goals: patient care, family support, research and education. Mace says that more support for at-home care can only come with increased public awareness that what was once dismissed as "senility" often is a serious physical problem.

Dr. Matthew Taybeck, director of the Maryland Office on Aging, believes that the public ought to be willing to give more support to families who want to take on the burden of caring for their elderly at home. If that support is not equal, it should at least approach what we're willing to give to institutions."

Taybeck cited the newly developed Family Assistance Demonstration Program as one way the state is trying to help families who care for the elderly at home.

Using a complex formula to determine the difference between the care a family can afford, and the actual cost of the care required, the state has set up a system for payments. The maximum amount a family can receive in one year is $2,000.

But even if this pilot program—currently covering 40 Maryland families, 13 of them in Montgomery County—is a success, its restrictions will exclude Bessie Jackson and others like her from assistance. Family, as the program's regulations define it, does not include the sick person's spouse.

Taybeck admits that this is ludicrous, but said, "The public policy notion remains that it is the duty of the spouse to provide such care. Perhaps as this notion and public awareness evolve, the rules can be changed."

It may already be too late for Bessie and Henry Jackson. Recently, Mr. Jackson fell in his apartment and suffered a broken hip. He is hospitalized and according to his doctor, Allen Mondzac, learning to walk again will be "an excruciating, if not impossible" task for him.

Mondzac believes that patients like Jackson receive better care at home—if they have the kind of dedicated family that Jackson has.

But now, he said, Mrs. Jackson may be forced to consider a nursing home, because the physical burden of caring for her husband in his present condition "is simply too much for any one, two or three people."

ROCKVILLE, MD., *March 16, 1980.*

Congressman M. BARNES,
U.S. Congress,
Washington, D.C.

DEAR CONGRESSMAN BARNES: In accordance with our meeting on February 21, 1980, I am sending you my suggestions relating to the improvement of the medical and Social Care Services conditions for those suffering from Alzheimer's Disease and their families trying to provide them with loving and efficient care.

I am also forwarding to Senator Pepper and to Phil Donahue copies of these suggestions. It is my hope that Congress can address these matters through appropriate legislation and that Mr. Donahue perhaps can raise the awareness of the public by discussing the illness and its effects on families and on society.

Here are my suggestions:

1. That families caring for those with Alzheimer's Disease should be subsidized individually in equal parts as would a Nursing Home facility.
2. That Medicare should include coverage of Chronic and Custodial Care Needs.
3. That the amount of time provided by Social Service Homemakers be increased to a reasonable amount of time dependent on need and circumstances. That the seriousness of this type of Support be made clear.
4. That increased Day Care Centers for Senior Citizens be established with special attention being paid to the particular needs of Alzheimer's sufferers.
5. That Night Homemaker Care be provided as night time care is almost always the most needed and always excluded from Homemaker Services as they presently exist.
6. That money for Research into Alzheimer's Disease be allocated in the hope that a cure or a treatment can be found.
7. That the Medical and Social Service professions be educated specifically as to the decent and humane treatment of patients with debilitating brain damage disease and of their families. That it be made eminently clear that adults suddenly afflicted with this illness in their adulthood when they are and have always been fully capable, functioning and independent individuals are neither children nor pets. They are sick people with special needs and fears specifically related to the changes that are occurring within their minds and their bodies. The language and care needed to treat these patients and their families need special attention and development.
8. That the decision for Social Services not remain in the hands of one individual Social Worker.
9. That a File of the History of a family be kept in a Central Place that can be released with Permission so that the poor family in need of help does not have to repeat and repeat the story of their need over and over again to each different Agency, Hospital and Service. Believe me, there is little as oppressive as that.
10. That present programs which include some financial support to children caring for ill parents be amended to include spouses caring for their mates.
11. That elderly couples should be treated independently under the Medicare/Medicaid System so that a dependent and ill spouse can receive extra financial aid without depleting the healthy spouse of a lifetime's earnings or causing the healthy spouse to fraudulently represent his/her financial situation.

Thank you for your help in this matter. I respect your efforts on my behalf and on behalf of the many other families still in such desperate need. I hope for all our sakes that you are successful in pursuing these goals. I am happy that we talked and should you need my help in any way, please let me know.

Sincerely yours,

BESSIE JACKSON.

U.S. HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
Washington, D.C., March 11, 1980.

DEAR MRS. JACKSON: I want to thank you for taking the time to come in from Rockville and share your experiences concerning Alzheimer's Disease and home health care with our staff. I want you to know that I share your concerns in these areas. Our Aging Committee has been fighting for years to enact legislation to expand the Medicare program so that it provides the kind of homemaker assistance you would have found so helpful with your husband. At the same time, we have been trying to urge the appropriation of funds to research the cure and treatment of Alzheimer's Disease. Unfortunately, we have been unable to convince our House colleagues of the necessity for this kind of legislation.

I am sorry that I was not able to meet with you yesterday, but previously scheduled commitments in my own Congressional District would not allow me to be in Washington when you were in our office. However, I did contact Dr. Butler's staff at the National Institute on Aging. They suggested that you might wish to speak with Dr. Richard Irwin or Dr. Bernard Wortman who are top experts in this field. I have requested that they contact you to set up an appointment, but if you have not heard from them in a reasonable period of time you may wish to contact them directly at 496-1033.

I am so very sorry to learn of your husband's passing. I can only hope that ultimately we can join together to promote and enact these kinds of changes so as to spare others the terrible burden of pain that you have already experienced.

With warmest regards, and believe me,

Always sincerely,

Claude Pepper, *Chairman.*

Rockville, Md., *March 16, 1980.*

Phil Donahue,
Chicago, Ill.

Dear Mr. Donahue: I have watched your program through good times and bad and I admire you and the work you are doing in examining the many issues that you bring up.

The bad times that I referred to for myself relate to the years in which I watched and cared for my husband who was suffering from the debilitating effects of Alzheimer's Disease. It is the disease and the problems that it creates in our society under the present medical care and social care system that I wish to bring to your attention in the hope that you will discuss the illness, the present state of research and the lack of health care support for those who are sick with Alzheimer's and for their families.

I am enclosing various letters from Senators and Health and Social Care People and an article written on my husband and myself that appeared in The Washington Post. All of this material highlights how inadequate the Support services are, especially in regard to giving financial support to spouses caring for severely ill mates.

In this country, in this day and age, everyone cries out in dismay about people throwing their loved ones into Nursing Homes. Everyone in the Social Services professions cries out in favor of Home Care. But try and find support when you have an ill husband who you are trying to keep at home and whom you are trying to love and care for in the best way. My story is that of one who tried.

My husband died on February 5, 1980. But for many the problem continues as the enclosures on the illness and on the Association that has just been formed testify. And many of the elderly, those who in their prime adulthood, contributed much of their skills and energies to make this society a decent and humane one, are forced to end their days abandoned and ill cared for.

I hope you will read this letter and the material that I am sending to you and that you will devote one of your programs to examining this issue. If I can assist you in any way please contact me at any time.

Sincerely yours,

Bessie Jackson.

Washington, D.C., *December 21, 1979.*

Dorothy Gilliam,
Washington Post,
Washington, D.C.

Dear Ms. Gilliam: In accordance with our conversation of Wednesday, December 19, 1979, I am sending you a copy of the letter I have written to all support people who have assisted my mother and our family in the matter of keeping my father at home with us. I would be very grateful if you could call this situation to the attention of anyone who could be of assistance to us and also to a great number of other families who are experiencing these same difficulties.

As I indicated to you in our conversation, everyone agrees philosphically that the best place for the elderly sick is at home with their loved ones, however, few programs actually support this theoretical position with real help. At the moment our plan is to bring my father home from the hospital on Saturday and my mother is receiving piecemeal help from the County on a weekly basis. We have been in contact with Congressman Barnes' office and also with the Office of the County Leader, Mr. Gilcrest. They and our Social Workers and the Homemaker Supervisor of the Division of Social Services will make possible whatever help we are given.

Thus far our request for Emergency 20 Hour a Week Support has been rejected on the basis of contract disputes and no funds, and this from one of the richest counties in the country.

If we are to be successful in our aims, we need much more assistance as Mr. Jim MacRae of The Support Center, Inc. indicated in a letter he wrote on our behalf to all these offices.

The plight of a spouse trying to keep her mate at home needs to be addressed. Between the sincere professional theories and the possibilities under existing programs for real aid, there is a wide gap. Society needs to address this gap for into it fall a great number of the old and sick who are being taken from their homes and their loved ones after the many years in which they functioned and contributed to this, their society. They deserve better. Their families deserve better.

Thank you for your attention and compassion in this matter.

Sincerely yours,

JOANNE JACKSON YELENIK.

DECEMBER 16, 1979.

DEAR PRESENT AND FUTURE SUPPORT PEOPLE: This letter is a statement for HELP for what our family believes is best for all its members: Bessie and Harry Jackson, Joanne, Ron and Daniel Yelenik.

The life of an institution is its own—it has its own processes and dynamics. We see that now as a result of these few days being with my father in the hospital. We knew it even before these few days. The life of our family is lived in our homes where we gather together for celebrations, where we enjoy our Sabbath, where we talk about our work and our play and where we laugh, cry, yell and discuss our lives. At this moment in this period of all our lives, we believe that this is the best life for my father to continue to be exposed to—for him and for us.

It is in my parent's beautiful home surrounded by all that they love and have worked for all their lives that my mother can receive visitors, can do her chores, can see her loved ones. It is in this home where my father during his good moments can recognize his family, laugh with us, dance and listen to music, welcome friends, eat his meals, say our prayers which he still is able to say and watch the little boy, his grandson, grow and play. My parents both love children and sociability.

Why do we need help, and more help, at that? We pretty much need round the clock aid—someone to help him, someone to help my mother. Someone or ones to help us keep him and us together.

We need more help because clearly my father is getting sicker and weaker. His moods are changing and he sleeps more during the day and has greater difficulty walking and moving. He moves at everything more slowly. What is his day like?

Slowly waking up, being helped to dress and go to the bathroom—chores done, then what? He watches the scenes from nature that he still loves—the trees and flowers—he listens to the birds. He walks, inside the apartment, and outside, when he is able. He sees us all come and go—he responds how he can—and does respond—he listens—he tries to communicate—he tries to understand what is communicated to him—we try to understand what he tries to communicate. HE FEELS. His life which was once broad is now limited—his hands which were once gifted and busy are now held. His life is very limited. Would we want to make it even more so? He tries to do the best within these limitations—in a home with people who he loves and who love him. An institution will not feel his absence from its walls—we will all feel his absence from this, his home. He is trying his best. We believe we should try ours.

You all know what my mother has done for my father. With help, Yes! But mainly it's been my mother. What would be her life if my father were in an institution? She'd be worrying all the time about his care, his treatment—most importantly, she'd be there with him in the institution for great periods of time, for many days.

There would be little release or relief. My mother loves her home, her apartment, her friends. People visit—she does her chores; it's the pattern of her life and she comes alive with it. To wrench my father from that home NOW is to also deal with wrenching my mother from it. Wrenching also, even further, Daniel and Ron and me from both my parents and their share in our lives and ours in theirs.

We ask for help at this moment Recognizing that conditions may change—that my father's illness is progressive. My father's future is only one of getting sicker and dying. Each day that we all keep him where he is best off is a victory for my father and for all of us.

We need to pool information continually. We will do so. We know the ending is inevitable. All endings are. This statement ask that we enter together this new phase of round the clock Home Support. That we try it together with all the financial and personal help we can muster. We will then see for how long—for how well this is working out.

We commit ourselves to caring about the safety and well being of all those involved in this care: the homemakers, the social workers, the doctors, the Support Center and all members of our family.

We ask from our medical doctors advice to all of us on my father's condition and consistent evaluations of same.

We ask from the psychiatrists similar evaluations and also drug evaluations and recommendations to stabilize and handle all phases of my father's condition. Generally we have observed his moods to stay on the side of what his personality always was: gentle, optimistic and affectionate.

We ask from the County and Mrs. Peterson the maximum 20 hours of Home Support under the Independent Vendor program.

We ask from the Support Center that my father can continue to be a member of that small and loving community whenever possible for him.

We ask from the Jewish Social Services their maximum Homemaking Support; and that same aid from any other possible supporting Agency.

We ask from our Social Workers support, counseling and understanding of our objectives.

We ask that you help us find whatever extra help—financial or professional—that we can and we well do so also.

We commit ourselves to obtaining as much home equipment as is necessary to help my father, my mother, us and all those who care for him, be it beds, wheelchairs, etc.

We commit ourselves to handling for as long as we can financially the nightly care on a 12 hr. shift basis that we have found to be so excellent and helpful from Kelly Services, especially in the example of a very remarkable person.

We commit ourselves to give as much of our time and money as it is possible for us to give. Our energy, caring, interest and depth of affection seems clear, but we reinstate it again.

We commit ourselves to pooling and evaluating information from all to all at all times no matter how hard.

We commit ourselves to sharing doctor's statements and all relevant information.

We ask a lot and we know it. We think we are giving a lot also. We know you all are and we are grateful. We think it is important—one man, one family—yet the values seem clear. We ask that you all stay with us through this to see where it goes and what the results are for everyone.

None of you knew my parents when they were young. Only some of you know of their early lives. Suffice it to say that they are good people who worked hard and loved well. They are victims of this illness. Yet they are fighting it together still. They love each other still. To us there is still much beauty in my father. The magnificence of his face is like the strength of his character and even like the strength of his frail, but strong body. The force of my mother's character and her integrity, I think you have all felt.

They are of the age to ask for professional help. They are of the need.

Thank you for your attention.

Sincerely yours,

JOANNE JACKSON YELENIK.

THE SUPPORT CENTER, INC.,
Wheaton, Md., December 18, 1979.

CURTIS VANOVER,
Department of Social Services, Montgomery County,
Rockville, Md.

DEAR MR. VANOVER: I regret that I was not able to attend the meeting of Friday, December 14th, regarding Mr. Harry Jackson.

Because I was unable to have direct imput at that meeting, I would like to state the role of the Support Center and my concerns to all persons who are involved.

The role of the Support Center in this case has been, and will continue to be, to provide day care services to Mr. Jackson on Tuesdays and Thursdays until such time as, (1) the family requests that these services be discontinued, or (2) Mr. Jackson's condition deteriorates to the point in which we are no longer able to adequately care for him.

Since October 1978, I have worked closely with Mr. and Mrs. Jackson and their family. I have been very impressed with the commitment each of them has made towards continuing to care for Mr. Jackson in a family setting. Mr. Jackson has responded very favorably to this nurturing and loving environment. It is clear to me that Mr. Jackson's needs are best met in this home situation. Furthermore, we at the Support Center have tried to continue caring for Mr. Jackson in this same nurturing way on Tuesdays and Thursdays.

Mrs. Jackson; here daughter JoAnne Yelenik; and her son-in-law, Ron Yelenik, have requested very little in the way of services during the seven years Mr. Jackson has been ill.

It is my understanding that the Department of Social Services has been providing one day of homemaking services to the Jacksons per week. Mrs. Jackson needs much more in the way of supportive services.

Mrs. Jackson is a rare and remarkable woman, but we cannot continue to care for her husband without more help. I believe the Department of Social Services should respond favorably to the effort which is being made by this family.

It is my understanding that Homemaker Services are considering removing their services from the Jackson home. This distresses me greatly. Homemaker services, instead, need to be increased.

We are dealing with a very unique situation—one which does not occur often. We have, in the case of the Jacksons, a family which is committed and concerned. This situation requires speedy and supportive action on the part of the Department of Social Services.

I urge you to give special consideration to this case and increase the support systems for Mr. and Mrs. Jackson.

Doing anything less than this, would be counterproductive to any decent service delivery system.

Sincerely,

Jim MacRae, *Director.*

What Is Alzheimer's Disease

Alzheimer's Disease is a disorder of the brain, causing loss of memory or serious mental deterioration. It is estimated that the disease affects from 500,000 to 1.5 million middle-aged and older Americans.

The terms presenile and senile dementia are used to describe any kind of severe mental impairment in older individuals. Many of these persons are victims of Alzheimer's Disease. Others suffer from a variety of other conditions. Diagnosis of the specific type of dementia is very important since some types, other than Alzheimer's Disease, can be effectively treated.

At first, patient's suffering from Alzheimer's Disease exhibits only minor and almost imperceptible symptoms that are often attributed to other illnesses. Gradually however, the person becomes more forgetful. As memory loss increases, changes also appear in personality, mood and behavior. The person may neglect to turn off the oven, misplace things, take longer to complete a chore that was previously routine or repeat already answered questions. Judgment, concentration, speech and physical coordination may also be affected. Some individuals show confusion and restlessness and may require special assistance.

There are many patterns in the type, severity and sequence of mental changes in this illness. The symptoms are usually progressive, but there is great variation in the rate of change from person to person. In a few cases, there may be a rapid decline, but more commonly, there are long periods with little change.

Although the person with Alzheimer's Disease is often unaware of, or may deny the full extend of his or her limitations—especially late in the course of the illness—the development and course of the illness are a source of deep frustration for those afflicted and for their loved ones.

As yet, the prevention or cure of the disease is not known. However, medical care can relieve many of its symptoms and proper guidance can assist the person and family in coping with the illness.

THE BENEFITS OF AN ALZHEIMER'S DISEASE ASSOCIATION

This organization can offer support to families, encourage additional funding for treatment and research, generate increased visibility of the problem, and encourage the continuing education of doctors and nurses in the management of the disease.

* * * * * * *

Linda E. Nee,
LCSW Advisor.

NEWS FROM THE NATIONAL INSTITUTE ON AGING

In recent years, changing attitudes among physicians, researchers, the media, and the general public have begun to whittle away at the myth that "senility" is inevitable in old age, untreatable, and results exclusively from a hardening of the arteries in the brain. At the same time, Alzheimer's Disease has come to the forefront of consciousness as a major and significant public health problem and as a probable cause of at least 500,000 cases of serious mental impairment in elderly Americans.

The costs of Alzheimer's Disease are incalculable in terms of both financial loss and personal and family anguish. However, in 1977, when the National Institute on Aging (NIA) launched its efforts to encourage research on the causes, cure, and prevention of Alzheimer's and related diseases, less than 0.2 percent of the $24 billion spent by the federal government on health services to the elderly went to research on the chronic dementias. There remains a great deal of confusion with regard to the causes, symptoms, diagnosis, and treatment of Alzheimer's Disease.

One approach to aiding the victims of Alzheimer's Disease and their families is research. Recent advances in a number of fields have defined directions for research scientists and have outlined possibilities for future studies. One currently being explored is that an enzyme replacement therapy might be able to alleviate the symptoms of Alzheimer's Disease in much the same way that L-dopa works in Parkinson's Disease. It is also possible that a breakdown of the immune system—the body's first line of defense—may be responsible for the development of Alzheimer's Disease. Other avenues of research involve the role of slow or latent viruses and the presence of heavy metals in the brains of persons who have died with Alzheimer's Disease.

In keeping with its concern for the quality of life in the later years, the NIA funds research on the organic brain disorders of old age at universities, medical schools, and other research institutions; conducts research in the Institute's own laboratories; and looks at such issues as risk factors in senile dementia under the auspices of the NIA epidemiology program.

A major goal of currently supported research projects is to find the cause or causes of Alzheimer's Disease and, in this way, an effective treatment for it. At several sites, patients and their families are being asked to provide information on past illnesses, occupations, places of residence, dietary habits, and family health. The data are analyzed for patterns that may indicate factors or causes common to patients. At the same time, the patients undergo physical and psychological examinations. Results of such studies have led to an intensive evaluation of three potential factors in the development of Alzheimer's Disease: traces of aluminum in the brain, viral infections of the central nervous system, and genetic factors.

At several other sites, NIA grantees are looking at the change most commonly associated with Alzheimer's Disease—the accumulation of neurofibrillary tangles in the cerebral cortex or outer layer of the brain. These studies are designed to determine the chemical composition and the role of normal neurofilament proteins and to find out how and why tangles develop. It is particularly interesting that these tangles have been found to develop in limited quantities—but seemingly without significant negative effects—in the nerve cells of more than 50 percent of the healthy aged population.

One project currently being planned in the NIA Laboratory of Neurosciences involves a study of the changes in the way different regions of the brain handle nutrients in patients showing marked confusion and memory loss. NIA scientists also plan to study alterations in regional brain metabolism in healthy people in association with changes in their ability to perceive, think, and remember over time.

In addition, the Institute's Epidemiology, Demography, and Biometry Program hopes soon to initiate support of research on a community-based group of persons—some having senile dementia and others as controls—to provide a better definition of diseases of this type and to identify associated risk factors.

Until recently, the victims of Alzheimer's Disease and their families have had to proceed as best they could. Now research has led to new and potentially promising insights. In the meantime, we are witnessing the growth of groups throughout the United States and Canada—as well as a new national organization—through which affected families are generating interest in and research support for this still mysterious malady. The National Institute on Aging supports the efforts of those dedicated to working against senile dementia and those who would devote their time and energy to providing information and assistance to others.

MARIAN EMR,
Public Information Specialist.

LOCAL RESEARCH PROJECTS SEEKING PATIENTS

The Clinical Center, National Institute of Mental Health, Bethesda, is looking for patients who have been recently diagnosed as having Alzheimer's Disease and who are still capable of a fair amount of independent function and self-care. The subjects should be 45 and older (preferably 45-65) and have no significant medical and/or psychiatric disorders. Patients meeting the criteria will be admitted for a 1-4 week study. Complete neurological, medical, and psychiatric evaluation will be followed by a trial of medications. There is no charge for this hospitalization. For further information, call collect: Walter H. Kaye, M.D., (301) 496-1891.

Also, the Clinical Center, National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, is looking for patients within the age range of 18-75 years in the early stages of Alzheimer's Disease who have memory loss or confusion and no serious medical illnesses (heart disease, kidney disease, or liver disease). Patients will be admitted for about 3 weeks and will receive a complete physical exam and tests to rule out any treatable causes of dementia. There is no charge for the hospitalization. For further information call collect: (301) 496-4149.

HELP AT HOME

In the future, I will use this column to respond to questions on home care. In this, my first column, I want to share with you some thoughts on memory loss.

Alzheimer's, as you well know, is a disorder that severely affects a person's ability to remember. The patient's failing memory is not within his power to control. It is as much a part of his disease as a rash is a part of measles. No amount of wishing, hoping, or praying will either eliminate the rash in measles or bring back the memory of the patient with Alzheimer's. Those who care for such a patient must understand and accept this fact before they can begin to cope with this disease.

This failing memory presents overwhelming problems for the victim of the disease. It embarrasses him. He cannot remember the names of friends, or how to carry out routine functions at the office. He makes light of or gives vague answers to questions instead of admitting that he cannot remember. He begins to doubt his intelligence or he fears he is going "crazy." His self-image slips. He is not the person he used to be but does not understand what is happening to him. Any one of us would be afraid, angry, and very anxious if we saw our mental functioning slip away and were unable to halt the steady decline.

Family and friends can at this point in the patient's illness offer more than medical science to date. Frequent reassurances that the patient remains a loved one with dignity and self-worth can best make him feel wanted despite his growing deficits.

Please send questions for this column to Alzheimer's, 819 Aster Blvd., Rockville, Md. 20850.

SALLY YOUNG, *Registered Nurse.*

SUBMITTED FOR THE RECORD BY MARIE-LOUISE ANSAK, EXECUTIVE DIRECTOR, ON LOK SENIOR HEALTH SERVICES, SAN FRANCISCO, CALIF.

METHODOLOGICAL CONSTRAINTS OF THE MEDICARE 222 DAY CARE DEMONSTRATION PROJECT

A report was recently released by the National Center for Health Services Research summarizing the cost and effects of day care services as seen in a Medicare demonstration project (NCHSR, 1979). The study itself addresses a critical problem area, alternatives in long-term care. Unfortunately, because of methodological and logical problems inherent in the design and implementation of the project, the study really raises more problems and questions than it answers. Instead of identifying many of these problems, the authors of the report chose to make strong conclusions regarding the cost impacts of day care; conclusions which are unwarranted, misleading, and potentially very damaging to the lives of millions of elderly who will be facing the needs for long-term health care.

The study has been referred to as the Medicare 222 demonstration and the report is entitled, "Effects and Costs of Day Care and Homemaker Services for the Chronically Ill." Using waiver authority under Section 222 of the 1972 Title XVIII Social Security Amendment, Medicare reimbursement was given for services provided through four day care programs across the country. The research and evaluation of these demonstration projects were given to an outside contractor, Medicus. Because of a series of problems and difficulties encountered throughout the data collection period, the evaluation contract with Medicus was withdrawn and the intramural research staff of NCHSR took possession of the data and prepared the final report.

The study as presented reflects many methodological and logical flaws, some of these being:

1. The study has limited generalizability.—The four centers involved in the study were chosen in a non-random fashion and were unrepresentative of all the centers which were in operation at the time. Projects were selected through competitive bidding with the day hospital model in mind. What would be true of this sample of day centers would not necessarily be true of the hundreds of other day centers operating throughout the United States.

2. The four centers used in the study were not even similar to each other.—One program was an established day hospital providing intensive rehabilitative services while another project consisted of a number of newly-established day centers providing a variety of social and health services. Indicative of some of the variation between sites is the daily cost for the various centers which ranged from $18.54 for one day care program to a high of $88.17 at another. Certainly, this difference is more than geographic variation. It indicates substantive differences between the programs being studied. To report that the average cost for day care is $52 per day or to imply that all of these projects are providing similar services is not only seriously misleading, but also reflects poor research method.

3. Demonstration programs do not reflect the actual experience of operating programs.—The Medicare 222 day care project was a time-limited demonstration. Centers were asked to develop their programs, serve participants for one year and close down. This artificiality has serious implications for the validity of the data. Some of the day care centers never reached full census, and because of fixed costs their daily costs were much higher than would have been expected if they were operating more stably. In some cases, participants understandably refused to get involved in the program knowing that their involvement would be time-limited and soon they would be forced to change. Most of the programs incurred a number of costs related to the development and demonstration of the program which would not have been necessary for ongoing operation. Because demonstrations are different from operating programs, the researcher cannot directly apply findings from a demonstration to conclusions regarding policy. What is needed instead is more information gathered from ongoing, stable operating programs. By the way, to anyone ever developing or operating program, it is abundantly clear that one year is not an adequate time frame to evaluate any program, especially a newly-developing one.

4. Although studying the impacts of day care on institutionalization, the study did not even limit itself to those at risk of such long-term care.—There were not specific standards for project eligibility which were used consistently across sites. In fact, because of participant recruitment problems, it was noted in the "Method" section of the report that most referrals were admitted to the project with the only ones being excluded were those who seemed in need of institutional care. In fact, the report itself suggests, "effective screening of patients to limit those served to patients 'at risk' of institutionalization would improve cost-saving prospects. . . ." By accepting healthy people and rejecting the more frail, the project deterred itself from its originally intended objective. It seems that an intensive health care program was established to serve a realtively healthy population. Certainly the impacts of the program will not be found if those for whom the program was intended are not the ones served.

5. The project made no attempt to provide management control over costs.—This is in part an unintended consequence of demonstration. The programs participating in the project were told to report their costs, but were not given any incentive to control those costs. As a result, costs for the Medicare demonstration projects were much higher than costs found in similar Medicaid programs. In addition, criteria specification, service program matching, optimization of treatment plan, client benefit, and program efficiency—were all things that were not discussed or incorporated into the demonstration programs. Without these management controls, the programs undoubtedly suffered and costs were likely inflated.

6. The study ignored large bodies of conflicting information from a number of operating programs.—The day care report described the findings of its study and referred to another study done by one of the authors, but gave no recognition or even acknowledgment of information available from a large number of operating Medicaid and Title XX day care programs and projects. In California and Massachusetts, for example, Medicaid has reimbursed a number of day health programs at rates far below those reported in the 222 studies. These programs were often better controlled and more tightly monitored than the Medicare projects, yet mention of their existence was not even made.

7. There is a difference between the real and ideal world.—The basic problem with the 222 demonstration underlying many of the above criticisms is the basic difference between a real world and a theoretical or ideal world orientation. Laboratory research addresses a theoretical ideal world. People are randomly assigned to conditions, human beings act in predictable and objective fashion, services can be turned on and turned off, people can be manipulated according to the needs of the research design. While this works in a laboratory setting, it does not in the real world: we can randomize rats but not people with real needs. Knowing that a project is limited dissuaded a number of people from getting involved in the service program. People who are denied services because of the needs of research are not the same as those who never would have received them. The real world is not the ideal world. Policy-relevant research, however, much address the real world. Randomized designs are not desirable if they do not realistically address the problem. Policymakers need to look to information gathered from real world settings in making decisions regarding the needs of their constituents.

A fuller presentation of some of the methodological and logical limitations to the 222 day care study is being prepared and a copy of the full report will be submitted to the committee upon its completion. It is important, however, that policymakers be aware of the limitations of the 222 Medicare day health and homemaker demonstration project. There is an adage in research that weak research replaces no research and good research ultimately replaces the weak. It is important that information on ongoing stably operating day care programs be gathered and organized so that we may address from a real world perspective questions regarding the value and cost of day health care.

APRIL 21, 1980.

Hon. CLAUDE PEPPER,
Chairman, House Select Committee on Aging,
Washington, D.C.

DEAR MR. PEPPER: We are writing to you as Chairman of the Select Committee on Aging to bring to your attention some of the progress and some of the problems relating to adult health care in the United States.

The critical and growing need for long-term health care has advanced the growth of the nursing home industry as the primary health care response. For many frail elderly, this response has been neither adequate nor appropriate. Adding more nursing home beds would not alleviate the disruption to family life and independent living caused by premature or inappropriate institutionalization. Specifically, from a number of studies 20 percent or more of those in long-term care institutions could have been more appropriately served in community settings if options such as adult day health and home health services were available.

Adult day health centers first emerged in the U.S. in the early seventies as an important community-based service in the continuum of long-term care. The movement has grown dramatically from a mere handful of programs to approximately 600 programs operating today. Funding comes from a variety of sources: Medicaid, mental health, social services, private funding, community funding, and insurance. Medicaid, the primary reimburser of long-term care, has acknowledged the importance of adult day health services by including it as an optional service. Seven states have affirmed the importance of this program by providing Medicaid reimbursement for adult day health services; additional states are actively considering their provision. Today, over 125 centers in these seven states receive Medicaid reimbursement for day health services. Most of these adult day health centers are grassroots organizations, developed largely by non-profit, community-based groups to met local needs. This grassroots support is indicative of the important needs being addressed by this program.

In addition to the fragmentation of funding, we, as planners, administrators and evaluators of adult day health programs, see two problems facing this growing long-term care service option. First, there is the misconception held by some policymakers that the continuum of care is an alternative to adult day health. The purpose of a continuum of care is to coordinate and integrate services, but it cannot do so unless all the service components are first in place. Thus, adult day health does not compete with, but is an essential component of any service continuum addressing long-term health care needs. Significantly, the U.S. Department of Health, Education and Welfare lists adult day health care as one of the core services in their newly-proposed National Channeling Agency Demonstration program.

A more critical problem is misleading information from a recent small-scale study of day care. The differences in individual programs make it difficult to conclusively evaluate the impacts of any new program like day health services. A recently released report by the National Center for Health Services Research (NCHSR) of the U.S. Public Health Service evaluated four demonstration centers (not statewide programs) with very different service mixes and costs, and concluded that the cost of day care was $52 per day. This report overlooked data from California, Massachusetts, New Jersey, and other states, identifying over 100 (non-profit and proprietary) Medicaid-reimbursed centers which are providing medically-oriented adult day health care at prices ranging from $15 to $25 per day. There is deep concern among those working with day health that such single, isolated studies will mislead policymakers in decisions regarding the future role of day health in long-term health care.

We respectfully request that the House Select Committee on Aging review the progress and program experience of adult day health care in this country and consider it as an important component of any plan of long-term care reform. Specifically, we urge your committee to:

(1) Include adult day health care in your hearings and deliberations regarding options in long-term care;

(2) Call upon the Health Care Financing Administration to establish a specific division to coordinate, support and provide technical assistance for the development of community-based options;

(3) Establish legislation which comprehensively deals with the problems of long-term care and includes community-based services, such as day health and home health, by: incorporating these community-based services into the Medicare benefits package; and strengthening the role of these services in the Medicaid system by allowing the states the option of providing coverage for certain low income aged, blind, and disabled individuals who need in-home and day health services on a regular basis, but are not categorically eligible because their incomes exceed the assistance standard.

Adult day health care can provide the frail, disabled elderly with the services they need while allowing them to remain in their community. It can do this, not by adding additional costs, but by substituting community-based services for costly institutional care. We urge you and your committee to use your influence for the advancement of this service alternative and the overall improvement of long-term care.

Thank you for your time and consideration.

Respectfully,

Marie-Louise Ansak, Executive Director, On Lok Senior Health Services; California Association for Adult Day Health Services; Charlotte Hamill, Associate Director for Planning and Program Development, Burke Rehabilitation Center; Anne Klapfish, Program Director, Adult Day Health Services of Massachusetts; Carol Kurland, Chief, Bureau of Social Care Programs and Medical Day Care Coordinator, Division of Medical Assistance and Health Services, State of New Jersey; Brahna Trager, Health Consultant; Dr. S. J. Brody, Department of Research Medicine, University of Pennsylvania; Judy Canterbury, Nursing Supervisor, Adult Protective Services; Virginia M. Hart, Supervisor, Program Development Section, Bureau of Aging; Dennis Kodner, Director, Planning and Community Services, Metropolitan Jewish Geriatric Center; Barbara Sklar, Director, Geriatric Services, Mount Zion Hospital and Mecial Center; Rick T. Zawadski, Ph. D, Research Director, On Lok Senior Health Services.

SYNOPSIS OF THE DEVELOPMENT OF ON LOK SENIOR HEALTH SERVICES

On Lok Senior Health Services started in 1972 as a day health center, a facility in the community offering services to the frail elderly who otherwise would have had to be placed in nursing homes. At the day health center, the elderly received medical supervision; nursing care; physical, occupational, speech, and recreational therapies; meals and dietary counseling; social services; and assistance with activities of daily living, such as grooming, bathing, etc. On Lok provided transportation to and from home to the center, physician's offices, clinics, etc., with specially equipped vehicles.

From 1972 to 1975, this project was funded as a demonstration project by HEW's Administration on Aging. In 1974, On Lok was able to negotiate a pilot project with the California Department of Health Services (Medi-Cal) for reimbursement of day health services. On the basis of their good experience with this type of care, a bill (AB 1611) was signed into law in California which made "day health services" a generally available benefit to the elderly in the State. Today, there are several "Day Health Centers" in various parts of the State offering such services.

From 1975 to 1979, On Lok, with the help of a "Model Project" funded again by the Administration on Aging, expanded its services. It was learned that a whole range of services was necessary to meet the ever changing needs of the handicapped elderly. One of the foremost problems in On Lok's district is housing. A plan for a specially designed facility, including living units and a day health center, was designed and a loan from HUD and private funding were obtained to construct "On Lok House" at 1441 Powell Street. This building is presently under construction and will be completed in September 1980 and will offer housing to 54 elderly. At the same time, during this model project period, On Lok developed a home health service component and a social day care center for those who no longer needed intensive medical supervision and rehabilitation.

One of the problems in developing and maintaining a non-profit, community-based, long term care system is the reimbursement and funding mechanisms presently available for health care in the United States. Strictly speaking, public and private insurances at best only offer minimal reimbursement for community-based supportive services—the emphasis is on payment for stays at acute hospitals and nursing homes. Organizations like On Lok have to seek funds from a myriad of sources, each with its own eligibility and reporting requirements.

It is for this reason that On Lok approached the Health Care Financing Administration (Medicare) in 1978 and asked for a novel approach. A package was developed which paid heed to the social and medical needs of the frail elderly. On Lok proposed to assume the responsibility for total care of its target population at a capitation rate (X $ per person registered per month for all care at home, in a nursing home or acute hospital). Medicare, recognizing increasing pressure to provide better and more comprehensive care to the elderly within the framework of limited resources, agreed to this project.

A four year codntract was entered into in February of 1979 and Medicare thus, for the first time in its history, has accepted the concept of a combination of social supportive services and medical care for the elderly. (For full description, see attached outline.)

On Lok, which has an extensive research department, is to demonstrate at reasonable cost the feasibility of a community-based, long term care system which is responsive to the needs of its clientele.

DAY HEALTH SERVICES FOR THE FRAIL ELDERLY

What it does.—Keeps the frail elderly in their own homes!

How it is done.—A multi-disciplinary team offers a complete evaluation at the beginning and regular re-assessments. A treatment plan is developed with the applicant and services are prescribed according to need.

What it provides.—Medical and nursing supervision, social services, physical, occupational, and speech therapies, nutrition (1-3 regular or special diet meals a day at the Center or delivered home), personal care services (grooming, laundry, bathing, escort services), transportation, supportive in-home services (shopping and cleaning), recreational-social activities (outings, discussions, films, crafts, health education).

What it costs.—To provide for a frail elderly person not needing 24-hour nursing care:

MediCal reimburses On Lok for the all inclusive package of Day Health Services for a participant an average of: $336.00.[1]

SSI provides this On Lok participant an average of: $147.73.

Total public sector cost per month: $483.73.

For the same individual, MediCal would reimburse a nursing home: $907.14.[2]

SSI would provide this person a monthly cash grant of: $25.00.

Total public sector cost per month: $932.14.

What it could save.—One person in day health services instead of a nursing home saves the State: Per Month—$448.41; Per Year—$5,380.92.

ON LOK DAY HEALTH SERVICES: ITS IMPACTS ON THE FRAIL ELDERLY AND THE QUALITY AND COST OF LONG-TERM CARE A SUMMARY OF FINDINGS[3]

On Lok Senior Health Services is a community-based day program providing health and health-supportive services to the frail elderly who need these services to remain in the community. Presently On Lok is funded as a MediCal Demonstration Project and as an HEW-AoA Model Project in Aging. This is a summary of a study evaluating On Lok's Day Health Center: its impacts on its participants and on the quality and cost of long-term health care.

Thirty-two recently admitted On Lok Day Health participants were compared to a matched group of 32 elderly persons living outside On Lok's service area. Participants in both groups were assessed by an independent team of health professionals from the California Department of Health in May and November 1976; most (90 percent) kept diaries describing their health services and activities for the five-month interim between assessments.

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[1] Actual average reimbursement to On Lok during first 4 months 1978. This all-inclusive rate includes all above mentioned services.

[2] Based on MediCal reimbursement rates for comparable sized nursing homes in San Francisco. Their rates exclude physical, occupational and speech therapy and medical evaluation.

[3] Prepared by RTZ Associates for the California Department of Health pursuant to Contract No. 75-53942 with additional research support received through an HEW-AoA Model Project in Aging No. 90-A-493/02 as part of their evaluation.

A number of findings emerged from this study:

1. A majority of Day Health participants were eligible for institutional care and would have been in a skilled nursing or other protective facility without Day Health services; with Day Health, they were able to remain in the community.
2. Day Health participants were more frail, with more medical problems than the comparison group and generally lower in mobility and strength; yet they were living more independently and doing more for themselves.
3. Day Health participants were more socially active, having more trips out and more visits than those in protective environments.
4. During the study period, 94 percent of the comparison group remained at the same level of care; the remaining 6 percent died. Day Health participants showed more movement: 16 percent deteriorated and 22 percent improved.
5. Day Health participants expressed more satisfaction than the comparison group with the health services they received and with the neighborhood in which they lived. Day Health participants and community residents of the comparison group expressed higher satisfaction in each satisfaction area and with life in general than those in board and care and skilled nursing facilities.
6. The Day Health group spent significantly fewer days in skilled nursing facilities and yet received more health care, e.g. physician and therapy services, than the comparison group.
7. Even with adjustments for supplemental income and other government programs, the introduction of Day Health did not increase total government costs. Health care expenditures were lower in fact for day health participants. The cost of Day Health services were more than balanced by savings in skilled nursing care. Individual expenditures varied more across Day Health participants and fluctuated more for them over time, reflecting greater program flexibility and a greater likelihood of cost controllability.

CONCLUSIONS

The continuum of services with Day Health was compared to the traditional long-term health care continuum available to the frail elderly. The continuum with Day Health was found to be qualitatively different, providing slightly more medical and significantly more therapeutic services for the same or even slightly lower health care costs. More importantly, Day Health enabled participants to remain in their home communities, to continue their social activities, and to improve or maintain their functional independence. Along with higher expressed satisfaction, these measures indicated the positive impacts of Day Health on the quality of life of its participants and, in turn, on the quality of long-term health care.

ON LOK SENIOR HEALTH SERVICES: A COMMUNITY CARE ORGANIZATION FOR DEPENDENT ADULTS

PROJECT DESCRIPTION

Introduction

On Lok Senior Health Services is a model community-based health service program serving the low-income elderly of the Chinatown-North Beach district of San Francisco. Initiated in the late 1960's by a group of concerned citizens and health professionals from the community and incorporated as a non-profit organization, On Lok has been striving to develop a free-standing, community-based service system responsive to the total needs—medical, functional, social and environmental—of the dependent adult. The goal of On Lok is to provide quality long term care, that is, care that meets the needs of the participant and which is satisfying to him/her, and to provide such care at a cost below that spent for traditional long term care.

In October of 1978, On Lok Senior Health Services was awarded a Research and Demonstration Grant from the Office of Human Development to plan, develop and evaluate a Community Care Organization for Dependent Adults (CCODA). According to the provisions of that grant, On Lok will assume complete responsibility for the management and delivery of all health and health-related services to a population of functionally dependent adults qualified for long term care institutional placement. Building upon the management and financing principles of the health maintenance organization (HMO), On Lok will develop and operate a community-based long term care system, the CCODA.

Through waivers granted by the Health Care Financing Administration under the authority of Section 222 of P.L. 92-603, On Lok will be paid from the Long Term Care Trust Fund a monthly capitation rate for each participant in the CCODA. For that payment, On Lok assumes complete financial responsibility for the medical and social case management of the participant as well as for the delivery of all services, both those provided by On Lok staff and those delivered by other providers.

Project principles.

The CCODA project reflects the philosophy of On Lok's community board and is a result of their six-plus years of experience delivering outpatient services to the functionally dependent adult. The basic principles of this philosophy, many of which are shared by researchers and planners in aging, are as follows:

(1) The dependent adult wants to and should be allowed to remain in their homes and in their own communities for as long as it is medically, socially and economically feasible.

(2) The problems facing the long term care needy adult are multiple and interrelated; social isolation and malnutrition have direct impacts on health.

(3) An adequate long term care response must consider the whole individual; providing medical care without nutrition or social support ignores the problem and is an ineffectual response.

(4) Coordination of services without control over their delivery is insufficient.

(5) Comprehensive, single source funding is essential for the delivery of cost-effective long term care.

(6) Quality long term care is affordable within present budgetary restraints.

Project rationale

Long term care today consists of a patchwork of overlapping services. Most of the long term care dollar goes to acute and skilled nursing facilities, but many other discrete providers are involved. Funding for long term care comes from a number of sources: Titles XVIII (Medicare), XIX (Medicaid), and XX (Social Services) of the Social Security Act; and Titles III and VII of the Older Americans Act. This piecemeal approach to the funding of long term care has resulted in a fragmented and ineffectual long term care response.

A fragmented long term care service response results in unnecessarily high health care costs and less than adequate care for the dependent who are served. Dependent adults are rarely able to avoid institutions unless a wide range of supportive medical and social services are readily available. Yet, categorical funding is, by authority and purposes, usually designed to support single services rather than complete systems. Individual needs are structured to fit service agency reimbursement guidelines. As a result, some needs often go unmet.

Changes in level of care present other problems. A discharge worker in a hospital may recommend in-home services, but there is no way to guarantee those services will be delivered or the continuity of care maintained. Often the funtionally dependent adult, incapable of arranging for his own services, falls between the cracks and receives inappropriate or no services. Simply dealing with multiple providers and changes from one provider to another is itself more than many can endure. Relating to many different agencies and individuals, and retelling problems is an unnecessary and stressful burden for the dependent adult.

From a cost perspective, multiple discrete service providers have obvious disadvantages. Multiple administrations increase costs through duplication of functions. Separate billings, authorizations and paperwork add to administrative overhead. Indirectly, providers of discrete inter-related services tend to protect their own interests, and service industries grow independently without inter-service controls. With discrete providers working in competition, there are no incentives for increasing the independence of dependent adults or transferring them to less costly, more appropriate service programs. Thus, today's long term care system is a patchwork system built around the skilled nursing institution. It is an expensive, ineffectual and as is, unworkable system.

Recently, interests have turned to projects which coordinate services for the elderly. Many of these projects provide centralized, comprehensive evaluation followed by referral to a wide range of services. This type of service system, referred to here as a "brokerage" model, uses existing service providers and adds to it another provider to coordinate and link available services. Although when functioning properly these systems do provide some benefits to the participants served by them, this "brokerage" model has some distinct disadvantages. The coordinating agency, for example, can refer someone for services but cannot guarantee service delivery. Furthermore, a referring agency has no control over the discrete provider and his costs. Thus a "brokerage" system is only as good as its weakest discrete provider. Some cost savings are produced because of more effective long term care placement in such models. However, added costs are also incurred by the added level of administration involved in coordination of services. Third, coordinating agencies often provide comprehensive evaluation, yet individual service agencies for their own reimbursement must often repeat these evaluations, adding to the cost as well as the stress on participants.

Another alternative for integrating services, and the one tested through On Lok's CCODA, is to have one agency coordinate and deliver all long-term care services. Through centralized management and delivery, a package of services can be provided which is responsive to the individual participant's needs. Service delivery can be guaranteed, because control of all service components are in the hands of the coordinating agency. Separate administrative costs are eliminated through centralized administration. In essence, the provider in a centrally managed and delivered long term health care system is given a broad range of authority as well as the responsibility and, with capitated reimbursement, the incentive for providing cost-effective care.

Project objectives

The overall objective of the CCODA demonstration is to apply the management and reimbursement principles of the health maintenance organization (HMO) to the problem of long term care by developing a model Community Care Organization for Dependent Adults (CCODA) and to evaluate the impacts of this health system on the quality and cost of long term care and on the health and welfare of persons who would otherwise be almost certainly placed in institutions.

This project will:

Develop and operate a centrally funded and administered community care system for meeting all health and health-related needs of dependent adults.

Measure the impact of capitated, decategorized funding (involving substantial provider risk) on the utilization, quality and cost of services provided to dependent adults.

Contrast the management efficiencies of the CCODA model with the fragmentation of patient management and budgets commonly found in presently operating systems of long term care as well as those offered in "brokerage" models.

Develop actuarially sound methods of budgeting the medical and social needs of dependent adults.

Produce a cost and utilization yardstick by which to measure the effectiveness of other models of providing services to dependent adults.

It is hypothesized that the CCODA will have the following impacts:

Health service patterns will be changed: Days of institutionalization, both skilled and acute, will be decreased while professional medical and therapeutic services will be increased: More health-related, social and supportive services will be delivered.

Quality of long term care will be increased: Participants will be functioning more independently; Participants will express greater satisfaction with the health service they receive.

Long term health care costs will be reduced: As compared to the cost of traditional long term care; As compared to costs in a "brokerage" model of integrated services.

Project location

On Lok serves the residents of a geographically limited area of San Francisco known as the Chinatown-North Beach district. This area can be geographically defined as the area contained by Bay Street, Market Street, Sutter Street, Van Ness Avenue, and the San Francisco Bay.

Almost 60,000 people live in this densely populated area, over half of whom are members of ethnic minority groups, speak little or no English, and live on incomes below the poverty level. According to the 1970 census, 15 percent of all those living in the area were persons 65 years and older. Those familiar with the community claim that even this statistic is much too conservative. Many more elderly reside in back rooms and alleys, unidentified by census takers. It has been estimated that perhaps as many as 20 percent of those in the area are elderly.

Population served

On Lok's CCODA is designed to serve the functionally dependent elderly in San Francisco's Chinatown-North Beach district, who are in need of long term care. Specifically, to be eligible for enrollment in the CCODA, participants must reside within On Lok's geographical service area and must be qualified for either intermediate or skilled nursing care according to criteria established by the California Department of Health Services.

Although enrollment is open to any qualified adult over 55 years of age, the vast majority of those entering On Lok are over 65 years of age. The average age of On Lok participants is about 76. A majority of On Lok's participants fall below the poverty level with about 70 percent qualifying for medical assistance (Medicaid). About 60 percent of On Lok's participants live alone and about half speak little or no English. The chronic health problems of On Lok's population are essentially the same as those of any other long term care population. Some of On Lok's participants require extensive medical care; others can benefit from extensive restorative therapy; and still others are in need of ongoing personal care and supportive services in conjunction with exercise to retard further deterioriation.

On Lok now serves approximately 200 participants. When in full operation, On Lok's CCODA will have an active caseload of approximately 400. Throughout its four-year demonstration, On Lok's CCODA will have served approximately 1,000 participants and will indirectly benefit the family and friends of participants and many other elderly.

The service program

Through its CCODA, On Lok provides all health services, i.e., medical, social and supportive services, required by the functionally dependent adult and coordinates these services with comprehensive medical and social case management. Comprehensive case management is a crucial component for the CCODA's effective implementation.

Case management is provided in two ways. First, a multidisciplinary health team regularly reviews the status of each participant. Together, the team works out a service plan which is responsive to the participant's medical, therapeutic and social needs. Members of the Assessment Team, in turn work with each participant directly providing all needed services. The Team physician, for example, is the participant's physician and is responsible for all the participant's primary medical care.

Second, the social worker/advocate is the agent of the participant and responsible for direct case management. Upon admission, a social worker/advocate is assigned to each participant and remains with that participant regardless of his movement in the program. The social worker integrates the needs and concerns of the participant with the resources available through the CCODA and provides psycho-social support to help the participant deal with situations that cannot be changed.

Not only are health services managed and coordinated through the CCODA's comprehensive case management function, but they are directly delivered by the CCODA service staff. Services may be delivered to participants in their homes, in one of On Lok's multi-level day centers, or if need be, on an inpatient basis in a skilled nursing facility or acute care hospital. Approximately 95 percent of all outpatient services are directly provided by On Lok staff. Inpatient services, which are provided under contract to the CCODA, are directly supervised by the On Lok staff physician. Thus, On Lok has complete control over all long term care health services.

Services provided through On Lok CCODA include: physician services, both primary and specialist; nursing services; therapy (physical, occupational and speech); comprehensive social services; dietary services, including meals and dietary counseling; transportation, both non-emergency transport to service programs and emergency transportation; home chore services; laundry; escorting, shopping and interpreting; home health services; and socialization services, including reality therapy, education, group exercises, crafts and work activities. Through contract with other providers and under supervision of On Lok's direct service staff, other long term care services are provided: acute hospital care; skilled nursing care; board and care; medications; radiological and radio-isotope services; clinical laboratory services; prosthetic and orthotic appliances; medical appliances and supplies; and ambulance service. Medical services provided by part time retained medical specialists include: podiatry, dentistry, optometry, audiology and psychiatry. For more detailed description of these services, refer to Attachment 1, Definitions of Reimbursable Services for the On Lok CCODA project.

Project staff

On Lok is guided by a policy board of health consumers and health professionals residing in or working in the On Lok service area. These board members are deeply concerned with the quality of health care provided to its community's elderly and serve on the board voluntarily as a manifestation of their concern. On Lok's community board defines program policy and approves all program contracts and grants. Dr. William L. Gee is the president of On Lok's Board of Directors.

Marie-Louise Ansak, as Executive Director of On Lok, is responsible for the planning and operation of the CCODA service program. Dr. Harry Lee, Medical Director, is responsible for the medical care delivered through the CCODA program. Physicians and health professionals from the community serve on a Medical Advisory Board, some members of which meet monthly as a Medical Utilization Review Committee. Together these groups review the quality of care provided through On Lok's CCODA.

Most services are directly provided by On Lok staff members, who represent all major disciplines involved in the provision of long term care. Specialty services not directly provided by staff are provided under subcontract with the CCODA and supervised by staff.

The research component of On Lok is headed by Rick Zawadski, Ph.D. Dr. Zawadski is responsible for the planning and implementation of the data management system and coordinates the evaluation and research components of the CCODA project. On Lok's research component works closely with a Research Committee, composed of On Lok Board members and researchers in the area.

Project funding and reimbursement

The planning, development and evaluation of On Lok's CCODA project is supported by Research and Demonstration Grant from the Department of Health, Education and Welfare—Office of Human Development Services, with funding from the Administration on Aging and the National Institute for Handicapped Resarch. This grant was awarded on October 1, 1978.

Funding for the service program comes from the Health Care Financing Administration's Medicare (Title XVIII, Social Security Act) program. Through waivers granted under Section 222 of Public Law 92-603, On Lok is reimbursed from the Long Term Care Trust Fund a monthly capitation payment for each participant in its CCODA. This single payment covers all health and health-related services provided to participants either on an outpatient or inpatient basis.

California State Department of Health Services has independently reviewed and supported On Lok's CCODA project. The concept being demonstrated by the CCODA project is consistent with demonstrations called for by California law (A.B. 998). As presently structured, however, the State of California is not involved in the financing of the project.

Project significance

Approximately 20 million Americans are 65 years of age or older. Of these, almost 2 million are in need of some form of long term care. A majority of these neither need nor want institutional care. Yet for most, the institution is the only long term care option available.

On Lok's CCODA directly benefits the 1,000 elderly it serves. Moreover, this demonstration will provide instruments for assessing and data for describing the cost and quality of traditional long term care and the relative "cost-benefit-effectiveness" impacts of expanded, comprehensively funded, centrally managed and delivered health services. This information will have direct implications, not only for other low-income, ethnic elderly residing in the inner cities, but for all elderly in need of long term care.

Homewood Retirement Center,
United Church of Christ,
Hanover, Pa., April 10, 1980.

Congressman Claude Pepper,
Chairman, House Select Committee on Aging,
Washington, D.C.

(Attention: Lou Bracknell).

Dear Congressman: We write to affirm our belief in and support of the concept of Day Care for the Elderly. It has been our privilege since January 1, 1976, to conduct a Day Care Program for the emotionally, socially, and/or physically needful residents 60 years of age or older in our community.

The average age of our participants is 76. In 1979, we served 43 individuals—16 male and 27 female—with 25 of this number being over 75 years of age. Thirteen of the 43 lived alone with no other support system. Adult Day Care goes way beyond the concept of the Senior Center; and this statement is not meant to reflect negatively on that very fine program. However, as the Day Care concept has developed in this part of Pennsylvania, most of our participants could not continue to function outside of institutional care without the supportive services they receive in Day Care. Our program is funded in part by Title XX funds and by a grant from the Pennsylvania Department on Aging.

Participants in our Day Care program who have a family support structure can remain under the influence of that support structure because Day Care provides alternative care while members of the family work outside the home, or it serves as a means of relief for those who are seeking to care for medically needful relatives in the confines of their home. For example, Day Care has supported the aging wife who is trying her best to care for here stroke afflicted husband. The same is true for children who are trying to care for their stroke afflicted mother at home. Our support has kept these people at home with their families rather than in institutions. Of course, those without any other support structure depend entirely on Day Care services to remain functioning and viable adults.

We are able to offer this service for $8.70 per day per participant. This cost does not include the cost of transportation which is provided by the York Transportation Club . . . another support unit in our community. Cost for transportation would probably add another $4 per day to our unit cost. This is well below the average cost of 24 hour per day institutional care in our community. Funding for the Day Care Program has not been adequate to underwrite all of our costs. Homewood Retirement Centers has underwritten some of the cost through in-kind contributions. We feel this is a reflection of our belief in and committment to the concept of Day Care for the Elderly.

We appreciate this opportunity to write in support of this very vital and worthwhile program.

Sincerely,

J. WILLIAM ANDERSON,
Administrator.

DEANNA R. NOBLE,
Day Care Coordinator.

McDONOUGH DISTRICT HOSPITAL,
Macomb, Ill., April 15, 1980.

LOU BRACKNELL,
Staff Director, Subcommittee of Health and Long-Term Care,
Washington, D.C.

DEAR MS. BRACKNELL: At the suggestion of Edith Robbins, I am sending you the enclosed material concerning the Day Health Services program at McDonough District Hospital for insertion in the record at the April 23rd House Committee on Aging hearings on Adult Day Care.

I certainly hope this material will be of assistance.

Sincerely,

GREG CASE,
Director of Gerontology.

McDONOUGH DISTRICT HOSPITAL,
Macomb, Ill., April 15, 1980.

EDITH ROBBINS,
Baltimore, Md.

DEAR MS. ROBBINS: Thank you very much for your phone call on April 11 and especially for your interest in the Day Health Services program of the McDonough District Hospital Department of Gerontology. We are very proud of our work here and welcome any opportunity to share our experiences. I certainly hope the information enclosed will be of assistance at the House Committee on Aging hearings on adult day care. A copy of this letter as well as the information enclosed has been forwarded to Lou Brecknell, Staff Director of the Sub-Committee on Health and Long Term Care, for submittal to the House Committee hearings.

To assist you in your understanding of the materials enclosed, I thought I would tell you a little about McDonough County and its people. The 1970 census indicates that there are about 37,000 persons residing in semi-rural McDonough County. Approximately 20,000 of these individuals reside in Macomb, the county seat and home of Western Illinois University. Of the remaining townships, four have between 1,000 and 4,000 residents while 14 townships have under 1,000 residents. There are just over 5,000 county residents 60 years of age and over with just over 2,000 of them residing in Macomb. Approximately 1,300 of the McDonough County residents aged 60 and over have incomes below poverty level.

The Fellheimer Bequest has greatly assisted McDonough District Hospital in its attempts to address the special needs of older McDonough County residents. These monies have been utilized in attracting many physicians to this area, increasing medical services not only for the aged but for the general population. The bequest has allowed us to account for the special physical, psychosocial, and spiritual needs of the rural older population in designing the Day Health Services program and other programs of the Department of Gerontology. In short, without this bequest, we feel we would not have had such a tremendous opportunity to address the specific health needs of the McDonough County older persons.

Again, thank you for your interest in our program for the aged at McDonough District Hospital. If we can be of any further service to you in your work, please do not hesitate to contact me.

Sincerely,

GREG CASE,
Director of Gerontology.

MCDONOUGH DISTRICT HOSPITAL

DEPARTMENT OF GERONTOLOGY

History

In 1973, Mrs. Lulu V. Fellheimer of Macomb, Illinois passed away leaving a generous bequest to McDonough District Hospital. This money was left to the hospital under the stipulation that it be used for health related services for elderly persons residing in the vicinity of Macomb, Illinois and to the extent possible giving preferential treatment to persons lacking financial means. Three years were spent in court determining the most appropriate interpretation of Mrs. Fellheimer's will. The courts determined that the bequest could be used for persons 62 years of age and older who reside in McDonough County. The court went on to say that the money could be used by the hospital in three ways: to support indigent inpatients; to assist in the recruitment of physicians to McDonough County; and to develop and operate geriatric outpatient clinics.

The McDonough District Hospital Department of Gerontology was established in April of 1977, in accordance with the bequest of Mrs. Fellheimer. This department was developed to provide older persons in McDonough County with health related services which support the individual in maintaining independence through prevention, maintenance or rehabilitation, to serve as a community resource providing information and referral to the aged, their families and other interested individuals and to play an instrumental role in community education concerning the abilities, circumstances and needs of older persons.

The Department of Gerontology has developed several programs since its inception in 1977. These include the Day Health Services program, a telephone reassurance program, annual flu immunization clinics, coordinating a county wide program for the terminally ill, a hearing evaluation and rehabilitation project and others.

DAY HEALTH SERVICES PROGRAM

Goals and objectives

The philosophical base of McDonough District Hospital's Day Health Services includes the conviction that simply supplying services is not enough. It is the primary focus of the program to ensure the maintenance of that sense of power and control over one's destiny which is critical to the integrity of the personality.

Older persons have substantial interest in health services and should therefore have a voice in the development of these resources and facilities both in their operation and delivery. Further it is believed that the geriatric individual is an important and integral element in our society from whose presence we can learn.

Based on this rationale, the following are the goals and objectives of MDH Day Health Services Program:

1. To provide a viable alternative to inappropriate institutionalization by the establishment of an adult day care program.
2. To offer, through a multi-disciplinary approach, an individualized plan of treatment and to provide encouragement for active participant involvement.
3. To implement a multi-disciplinary model which will be an integrated program of medical, social and therapeutic content.
4. To offer transitional services to facilitate the elderly persons' return to their homes from acute or long term care institutions.
5. To prevent social isolation and encourage social interaction for elderly individuals.
6. To foster effective nutritional habits through a well balanced meal.
7. To offer specialized transportational services to program participants.
8. To assist all participants' families in their efforts to maintain elderly in the home.
9. To provide a protective enviornment, retard deterioration and provide rehabilitative measures.
10. To provide, through the team approach, a supportive atmosphere in order that the individual may continue to direct their life and maintain their independence.

Developmental case history

This 83 year old male entered the Day Health Services program with degenerative arthritis in both upper and lower extremities, coronary heart disease, severe bilateral hearing loss, a hiatal hernia and vertigo. Though once an active business man within the community, in the past few years he had been home bound, and living alone. Due to the arthritis and lack of exercise, ambulation was very difficult. His self concept was quite low and he exhibited a great lack of self confidence. He seemed to have given up.

A care plan was set up for this individual which included physical therapy, daily exercises, involvement in constructive therapeutic activity, and involvement in counseling and instruction groups. Staff was alerted to provide positive reinforcement for accomplishments and to encourage him to help out around the Day Health unit as much as possible. He was instructed on how to deal with and prevent dizziness due to vertigo. In addition, instruction was given on how to decrease the liklihood of choking due to hiatal hernia, as well as how to self-administer the heimlich maneuver.

After one year with the program, this gentleman is able to ambulate indoors without assistance and out of doors with a cane. Weather permitting, he is now able to regularly walk the several blocks from his home to the downtown district. Through the program, he developed an interest in making leather belts and wallets and rubber link doormats. He now orders materials on his own and sells his products throughout the community.

By providing this gentleman with the environment and the skills to maintain independent function, he seems to have been able to re-kindle his desire for active participation in life.

Developmental case history

This 71 year old male with pulmonary emphysema, hypertension, arteriosclerotic heart disease, obesity, and cataracts was referred to us by the Public Health Department. At the time, he was living alone in a small travel trailer not designed for year round habitation. He exhibited, both behaviorally and verbally, a very low self-concept and an unhealthy dependence on others. He is a very bright and knowledgeable gentleman but at that time appeared to be unable to take the actions necessary for self care.

Since his admission to the program twelve months ago, his average attendance has been three days per week. The staff, as a team, has encouraged independence by focusing on the participant's abilities rather than disabilities. An atmosphere was provided within the Day Health unit where self help was matter-of-factly expected. Verbal self-abuse was generally not acknowledged. In regards to his medical condition, respiratory therapy was ordered and his emphysema and hypertension have been closely monitored. Dietary counseling through the hospital dietician was provided regularly.

The greatest success with this participant has been in a greatly improved self concept and ability to exercise control over the conditions of his life. After a few months in the program, he sought assistance in contacting an ophthalmologist and has had two successful cataract surgeries. At his suggestion, he was assisted in applying for subsidized housing in a new development and has now relocated. His personal hygiene and appearance have improved greatly with his increased self confidence. He has become very involved in small woodworking projects with another program participant and a close friendship has developed. Though very little weight loss has been recorded, the dietician continues to work with the participant.

This 70 year old female entered the program in January of 1980 with diabetes mellitus, asthmatic bronchitis, arteriosclerotic heart disease, and left shoulder pain. She lives with her husband who also has several chronic conditions. She had sought entrance to the program primarily because she felt a great deal of physical and emotional stress in dealing with her own and her husband's health conditions.

She was given instruction in diet control, medication, and infection control in relation to her diabetes. She has received respiratory therapy within the program and was assisted in acquiring home breathing equipment. Physical therapy was ordered for the left shoulder pain. She receives individual instruction from an occupational therapist concerning appropriate ways to deal with stress, especially through an exercise program. In addition, one to one support is given. She has attended several medical education discussion groups within the program where she has been very actively involved.

It is felt that this participant's greatest benefit from Day Health Services has been having the easy access to medical information and support.

ADULT DAY HEALTH SERVICES

Admission procedure

Stage 1.—Inquiry by the elderly person, a family member, or a professional person on behalf of the applicant.

Stage 2.—An interview is conducted either over the phone or in the Department by the Director to establish eligibility based on the admission criteria.

Stage 3.—An interview is conducted in the home with the participant and family members. The purpose of this is not to evaluate total functioning, but to provide a reasonable indicator of the appropriateness of Day Health Services for this particular individual.

Stage 4.—The prospective participant and family visit the facility. Explanation is given in regards to services offered, cost, transportation, etc.

Stage 5.—An interdisciplinary team meets to evaluate the applicant for participation.

Stage 6.—The prospective applicant receives a physical examination and the physician forwards an evaluation and recommendations.

Stage 7.—With the physician's written order, the applicant is accepted and a plan of treatment is set up.

1979 DAY HEALTH SERVICES PARTICIPANT REPORT

	Admissions	Discharge	Days Open	Total [1]
January	1	0	10	40
February	3	0	12	81
March	1	1	12	83
April	1	0	13	104
May	1	0	12	85
June	1	0	19	122
July	3	0	21	121
August	3	1	23	165
September	1	0	19	167
October	3	0	23	200
November	3	0	20	180
December	1	1	19	183

[1] Total number participants as of Dec. 31, 1979: 23.

Day Health Services—Referrals

Total number referrals	77
Total number accepted	29
Reason for nonacceptance (applications in process)	3
Referred to other agency	6
Not eligible	6
Individual not interested	31
Death	2

DAY HEALTH SERVICES PROGRAM

Admission requirements

1. Should be aged 62 or older.
2. Should reside within McDonough County.
3. Should be free from communicable disease.
4. Should have a personal physician.
5. Should be in need of a protective environment during the day because of a physical, social and/or mental disability.
6. Has moderate to severe difficulty carrying out activities of daily living in the home.
7. Should have a home environment which provides his basic needs during those hours he is not at the center.
8. Should be able to walk alone, or ambulate with the assistance of a wheelchair, walker, or cane.
9. Should be continent of bowel and bladder, or with an assistive device.

10. Cannot exhibit extreme mental confusion which manifests itself through harmful behavior. Individuals exhibiting mild disruptive behavior or who tend to wander will be accepted on a trial basis.

11. Must not require constant one to one staff supervision because of functional disability.

12. Cannot be a chronic alcoholic or drug addict.

13. Must be able to verbally or non-verbally communicate his needs to the staff.

CYO Adult Day Care Center,
Akron, Ohio, May 9, 1980.

Congressman Claude Pepper,
House Select Committee on Aging,
Washington, D.C.

(Attention: Lou Bracknell)

Dear Congressman Pepper: I would like to submit information into the Hearing Record an appropriateness and need for Adult Day Care Centers.

It is a unique and creative alternative to institutionalization. It provides community-based care while promoting independent living therefore maintaining the family unit.

Please note the two enclosures. One being a family questionnaire regarding each of our participants and the other an evaluation on the goal setting regarding participants.

Again, Adult Day Care is a needed and necessary community service.

Sincerely,

Martha French, *Director.*

CYO ADULT DAY CARE

CLIENT SATISFACTION COMPONENT

A total of 41 questionnaires were returned. Attached is a sample questionnaire with the breakdown of responses to each question.

The greatest need for participation in this program was seen as socialization (71 percent), followed by recreation (61 percent), and supervision (29 percent). 90 percent of the respondents reported a change in the client since enrollment in the program. 93 percent said they would recommend the program to other in the community.

The following is a summary of respondents to the questionnaire and their relationship to the participant:

Daughter—15; daughter-in-law—2; son—3; husband—4; friend—1; foster home—1; niece—1; wife—3; brother—1; brother-in-law—1; sister—0; sister-in-law—1; group home manager—2.

Sample of responses to question No. 4 regarding changes in participant since enrollment at CYO:

"Got up and dressed without coaxing"; "behavior has become more senile, program is helping to arrest the speed of deterioration"; "she no longer cries, she is more cheerful"; "she is a little more stimulated mentally"; "improved ability to communicate created a purpose to get up and go, stimulated his mind"; "enjoyment of going somewhere every day—he looked forward to going to CYO"; "less bored—seems stimulated"; "seems to enjoy life now"; "in her disposition—jealousy seems to be under control"; "more alert, more relaxed, has taken some responsibility for himself"; "needs are beyond services of center, withdrawn to home care"; "more responsive and alert"; "suffered a stroke and entered nursing home"; "he is more pleasant and cooperative around the house"; "showed interest in activities"; "mother talks enthusiastically about activities and friends and feels she has someone to turn to for advice"; "much happier and more independent"; "illness is progressive and he isn't able to do all the things he could when he started at the center"; "Thanks to the good nurse on duty who found the problem with her medicine"; "not as depressed"; "outlook on life is better"; "more self confidence, doesn't brood because she is not loved"; "blood pressure lower and happier".

Sample of additional comments:

"Your work with the elderly is wonderful. I hope that you'll be able to continue, you're offering more service than other groups." "You have added so much to my mothers' life. She really looks forward to coming every day and talking about what happend. Her experiences with you are a far cry from her days of watching TV, writing letters and taking naps at home." "Says none of the staff carry on conversation with the senior citizens other than a greeting. She feels this personal touch would be a great uplift to the spirits of many of these lonely people." "It was a great relief to me to know she was there properly taken care of while I worked." "I feel there is a need for such a program in the community. Felt the program was quite worthwhile." "Staff at CYO are pleasant and helpful and genuinely interested in clients welfare." "We were grateful for CYO and concern offered by the staff. She is now at retirement center."

QUESTIONNAIRE

The staff of the CYO Adult Day Care Center requests that you complete this questionnaire so that an evaluation can be made of how effectively our program is meeting the needs of your family member who attends our program. The CYO Adult Day Care staff appreciates your cooperation in promptly filling out and returning this form. This information will be kept confidential. If you have any questions about the form, feel free to call me at 253-4210.

Thank you.

MARTHA FRANCH, *Director.*

NOTE.—In the following questions, your relative or friend who attends our program will be referred to as the "participant".

1. I saw a need for the participant to be enrolled in the CYO Adult Day Care program for:

a. 25 recreation 61 percent.
b. 29 socialization 71 percent.
c. 2 nutrition .05 percent.
d. 12 supervision 29 percent.
e. 9 all of these 22 percent.
f. — other (please specify).

2. At the time of enrollment, I felt that the center participant could be helped by the Adult Day Care program. Yes: 41—No: 0.

3. Have there been any changes in the participant since he/she began coming to the Adult Day Care program? Yes: 37 or 90 percent—No: 3 or 07 percent.

4. If changes have occurred, please explain the nature and extent of these changes. (See attached.)

5. Do you feel that the Adult Day Care staff could improve this program? Yes: 6 or 15 percent—No: I am satisfied 29 or 71 percent.

If Yes, How?

6. Have you received any complaints or negative remarks about the Adult Day Care program? Yes: 3 or 07 percent—No: 38 or 93 percent.

7. Have you received any positive remarks about the Adult Day Care program? Yes: 28 or 68 percent—No: 7 or 17 percent.

8. Are there any other services that you would like the Adult Day Care program to offer to the participant? Yes: 8 or 20 percent-No: 24 or 59 percent.

If Yes, What?

9. Have the transportation arrangements for our program been satisfactory? Yes: 37 or 90 percent—No: 1 or .02 percent.

10. Has the staff of the Adult Day Care center been cooperative in keeping you informed about the progress of the participant in the program and in helping resolve problems relating to your family member's participating in our program? Yes: 30 or 73 percent—No: 6 or 15 percent.

11. To your knowledge, has the noon meal been satisfactory? Yes: 38 or 93 percent—No: 0.

12. Would you recommend the CYO Adult Day Care program to others in the community who might benefit from such a service? Yes: 38 or 93 percent—No: 1 or .02 percent.

Signature of person completing questionnaire and Date.

Relationship to participant.

Additional comments.

CYO ADULT DAY CARE CASE REVIEW

The staff at CYO conducts quarterly goal setting conference on each participant to assess progress toward the individual goals and set realistic goals for the next quarter.

Evaluator observed a conference and was impressed with the effort made toward establishing feasible goals which is often a difficult task in the area of adult socialization.

The records reviewed were selected at random (every other one), and a total of 25 cases were examined. The records were very well organized and complete. This program has developed useful forms to gather the pertinent information.

One of the difficulties in evaluating this program arises from the two distinct types of clients being served. One group of clients attend the center for socialization activities. Another smaller group of clients attend who need supervised care for a portion of the day. Not all the clients attend on a daily basis.

The evaluator concentrated on two areas when reviewing the records: progress toward individual goals and maintenance of health as measured by vital signs (weight, blood pressure, and pulse rate).

It is interesting to note that of the benefits of this program appears to be health related. Of the 25 cases reviewed this is the summary of the vital signs: 12—vital signs improved; 2—vital signs worsened; 9—maintained vital signs at fairly constant level; 2—no recent information.

Please note that I am not attempting to establish any causal relationships here. It does appear, however, that this program is meeting one of their objectives by maintaining and stablizing the health of some participants.

The following is a brief summary of the Quarterly Reports (see attached) on the clients' progress toward goals as rated by the staff. I grouped the numerical ratings on section No. 2 (progress toward goals) as follows: 1-3 poor; 4-7 fair, 8-10 good.

Good (clients)	14
Fair	5
Poor	3
No information (not attending at present)	3

I also thought it might be helpful to include a sample of some of the goals:

Encourage participation in group activities.
Make use of other areas in main room.
Discourage sleeping.
Involvement in individual craft project.
Encourage to report cancellations.
Promote adjustment to center.
Encourage attendance on regular basis.
Encourage client to assume center responsibility.
Discourage and extinguish "wandering" behavior.
Encourage interaction with at least one other participant.
Discourage dependence on SWAP worker.

In conclusion, this evaluator has been impressed with the quality of the CYO staff and the services delivered by this program.

Testimony Submitted by Lenore S. Hersh, M.T.R.S., Director Adult Day Treatment Center

Casa Colina Hospital for Rehabilitative Medicine, founded in 1936, is a comprehensive rehabilitation center delivering approximately $7.5 million in rehabilitation services each year. It serves in excess of 600 inpatients and 3000 outpatients per year. It is fully accredited by both the Joint Commission on Accreditation of Hospitals and the Commission on Accreditation of Rehabilitation Facilities.

Specific service programs offered by Casa Colina include a Children's Services Center (educational preparation and physical restoration for orthopedically and neurologically handicapped children); Hospital Services Center (inpatient stroke rehabilitation program, inpatient spinal cord injury program, inpatient brain injury program, inpatient chronic pain management program); Career Development Center (vocational evaluation and training); Adult Day Treatment Center (day hospital, preventive maintenance program, and personal disability adjustment program); Casa Colina Palms (retirement community for the elderly on limited incomes); and community clinics in arthritis, muscular dystrophy, cardiac work evaluation, pain management and stress, and brace and orthopedic services.

In June, 1975, Casa Colina Hospital for Rehabilitative Medicine initiated an Adult Day Health Treatment Program in response to a growing demand for an alternative health care system for the chronically ill and elderly disabled individuals who are medically stable and no longer need 24-hour inpatient care, but are still in need of skilled medical, rehabilitation, and restorative services. The trend to shorten approved lengths of stay for individuals on inpatient status has hindered the process of rehabilitation in physical functioning and psycho-social needs and/or caused deterioration of conditions by not allowing the individual to learn to become maximally proficient at his/her level of ability. Our program serves as an alternative to total institutionalization or as a transition from an acute hospital, long-term care facility or a home health care program, providing a therapeutic environment for personal independence of the chronically ill and elderly disabled when less than 24-hour skilled nursing care is needed. The program provides skilled medical, rehabilitation, and restorative services, along with supportive services to the patients and/or families/significant others, enabling the chronically ill and elderly disabled individuals to live in their own homes and participate in their home and community environment to the fullest extent possible. The Adult Day Health Treatment Center has helped prevent or postpone unnecessary utilization of inpatient hospitals or long-term care facilities.

The cost on a monthly basis, which covers the basic daily services of skilled nursing care, social services, therapeutic recreation services, and nutrition on a preventive maintenance level is $525 per month compared with $800 to $1000 a month in a skilled nursing facility. The cost on a monthly basis, which covers these basic daily services with emphasis on skilled nursing treatments, is $840 a month compared with $4600 a month in an acute care facility. The high cost of institutionalizing the chronically ill and elderly disabled demands that alternatives, such as Adult Day Health Care Centers, be established. These approaches are clearly less expensive and, if effective, have the promise of saving many tax dollars when achieving the positive goal of maintaining persons in their own homes in their own communities.

Casa Colina Hospital strongly recommends the establishment of Medicare reimbursement for Adult Day Health Care Services to the chronically ill and elderly disabled Medicare recipients. At this time, only the individual services, such as physical therapy, occupational therapy, speech therapy, etc., are reimbursable by Medicare. The daily per diem, covering the basic daily services, at this time is not reimbursable by Medicare. Our programs have been vendorized by the Developmental Disabilities Section of the California State Department of Health and by the California State Department of Rehabilitation to cover the daily per diem for those individuals who need the personal/disability adjustment training program. There are many private insurance carriers covering the daily per diem depending on what the individual's contract reads. There are many patients who pay through private financing or receive free care. There have been many Medicare recipients who qualified for our Adult Day Health Services, but they lacked private funds to afford it, or the free care funding was not available and, as a result, many have been placed in a long-term care facility.

I firmly believe the Adult Day Care Programs, which are the social models or the preventive maintenance models, should be financed under Title XX funding. These models compare to your intermediate care or board and care services. Title XX, at the federal level, mandates adult protective services, which is defined as services to keep people from being institutionalized. Unfortunately, many states, such as California and its counties within the state, do not recognize or meet the mandated adult protective services.

Adult Day Health Services compares to the services of a skilled nursing facility. Therefore, Adult Day Health Services should be recognized and reimbursed by Medicare. Adult Day Health Services are less costly than a skilled nursing home if you compare the daily per diem. A patient in a skilled nursing home, if they receive restorative services, such as physical therapy, occupational therapy and speech therapy, is billed separate from the per diem, just as it is done in many day health programs. There is much evidence, also, that skilled nursing facilities cannot handle the high level of skilled nursing treatment care that many patients need. The Medicare guidelines state that an individual is eligible for Medicare reimbursement in a skilled nursing facility if they need more than just help with eating, dressing, bathing, and taking medications at the right time. This should be the same eligibility criteria for Medicare to cover the cost of Adult Day Health Services.

I would like to place in evidence, as part of my testimony, the following case studies of patients that have been in our program:

Case study 1

This patient was a 72 year old woman with a diagnosis of Osteoarthritis, Arteriosclerotic Cardiovascular Disease, Orthostatic Hypertension, Cataracts, and Diabetes. Before being admitted into our program, she was hospitalized seven times between July of 1975 and January of 1976. She had been a dependent person all her life. Her husband spoiled her, waited on her hand and foot, and after his death, she went into prolonged immobility, bedrest, and dependency on others. There was a problem of management at home, because of her being very demanding and completely lacking any motivation for trying to help herself—she felt people should continue waiting on her. When admitted to our Adult Day Health Treatment Center, she showed evidence of being a very highly manipulative person, having passive-aggressive behavior patterns. The first month she was in the program, she did have physical therapy on an ongoing basis and one psychological consultation with our psychologist. After one month in the program, she was discharged from physical therapy and did not need any more psychological counseling. During the next month, through the activities of our Adult Day Health Program, her endurance level reached a normal range. We placed her in the role of helping others to lessen her dependency. She also got involved in cooking activities and now enjoys cooking and is able to handle preparing her own meals. She has purchased a mobilehome and is living by herself, but for a short time continued in our program on a three day a week basis to maintain her current level. She has now been discharged from the program and is living completely independently in her mobilehome, and is active in community living. Prior to coming into our Adult Day Health Treatment Center, the dollars that were spent on her hospitalization totaled a very large amount. Without our Adult Day Health Center Program, as an alternative health care system, she would have ended up in a long-term care facility for the rest of her life.

Case study 2

This woman, in her late seventies, had a stroke in June of 1975 and was admitted to Casa Colina Hospital in July of 1975 as an inpatient for rehabilitation. While a patient at Casa Colina, she showed tendencies toward being impulsive, became agitated for no apparent reason, and intially and intermittently felt depressed. She had a short attention span, was uncooperative, and a chronic complainer. Her endurance was low and she needed to have someone with her at all times. Upon discharge, she lived with her daughter who teaches school. It was a choice of being placed in a long-term care facility or becoming a patient in our Adult Day Health Treatment Center. When she was admitted to our program, her endurance was still very low. She had to take rest periods after an hour of activity. The first month, she also received occupational therapy for range of motion. Aftter one month in the program, her endurance had built up and she had reached an independent level. Through our lectures on nutrition, she has now developed good eating habits which she did not have premorbidly. She has also developed a good pattern of exercising which keeps her endurance level high. She was discharged from our program and is now very active in one of the senior centers in the community. The dollars saved by her being in our program are insurmountable compared to what the cost would have been if she had been placed in a long-term care facility in which she probably would have had to remain the rest of her life.

Case study 3

This is a 60 year old man who, in January of 1975, had a stroke, leaving him with a right hemiparesis and aphasia. After his condition was medically stabilized at the acute hospital, he was transferred to Casa Colina Hospital for an in-depth rehabilitation program. When discharged from Casa Colina, it was difficult for his wife to take care of him at home on a 24-hour basis because of her own health. The goals were set to make him more independent, give him a chance to interact through either verbal or nonverbal communication, and to build up his endurance to do things for himself. He received ongoing speech therapy which we reinforced through activities. He was given vocational testing, but showed no potential. Through the various activities, he did show good eye/hand coordination and manual dexterity. His communication skills had improved. He has many words in his vacabulary that he can say, and also has good technique in gesturing his needs. He ambulates independently with a quad cane now and needs no supervision for bathroom needs. Their private financing ran out and he was going to be discharged from our program. We were able to get the State Department of Rehabilitation to fund him in our program to help him become more self-sufficient in case his wife's medical stability did not stay up to a level where she could take care of him. He was taught kitchen skills and is able to prepare a breakfast, lunch, and dinner independently. Through the group counseling offered in our center, both he and his wife have adjusted well to his disability now, carry over into the home and community many things have learned through our program, and lead an active lifestyle with family and friends. When he first came into our program, besides speech therapy he had physical therapy and some occupational therapy. He was discharged from our program, there was a good chance of his wife not being able to handle many of his problems he had at the very beginning, and now as her own health flucuates up and down.

Case study 4

This woman, age 57, has a diagnosis of multiple sclerosis. She had led a very active lifestyle previous to her illness. Since developing multiple sclerosis, she had become a very dependent and demanding person. She had a very high level of anxiety and a manipulative behavior pattern. She played a very passive-aggressive role, making people feel she was completely helpless. Before being admitted to our program, she was at home all day with a licensed vocational nurse. She was very dependent in her activities of daily living and personal hygiene. She functioned from a wheelchair level. When she first came into the program, she did not want to push her wheelchair—she always wanted others to do it for her. We set our goals in the program for her to become more independent in her activities of daily living and personal hygiene and feel that she had a place in society, and not to feel that she had to be dependent on others. She attended the center five days a week while her husband, who is a professor at a local university, was working all day. Before she came into our program, he was ready to place her in long-term care facility because he could not affored to continue paying a licensed vocational nurse on a daily basis and it became very difficult for him to handle her when he was home. Without the Adult Day Health Treatment Center Program, her husband would have placed her in a long-term care facility.

Case study 5

This is a 52 year old man with a diagnosis of multiple sclerosis. The onset was in 1967. The disease has progressed to the point that he is at a wheelchair level. He was admitted to our Adult Day Health Treatment Center with a feeling of hostility as a result of his disability. There is a poor family life environment. He has difficulty getting along with his wife and children. He has a defeatist attitude. He leads an active fantasy life, has a very poor concept of himself, and his major coping mechanism is passive-aggressive behavior with strong dependency upon his family to meet his needs. That is what has caused problems within the family, as well as the fact that he manipulates the family to meet his needs through his physical complaints. To summarize where he was when he came into our program, he was highly dependent, a very passive-aggressive individual who had reached the point of feeling very defeated about life. He had very low self-esteem, and did not want to assume a responsible role in interrelationships with others. The goals we set for him in our program were to build up his endurance, to help him become independent in activities of daily living and personal hygiene, and to help him develop high self-esteem. He did accomplish most of these goals while he was in our program, but he was not able to continue after a couple of months because of lack of private financing to pay his way in the program. We have kept in contact with him and his wife. He has regressed back to where he was before he came into our program, and even more. There are many days that he does not even get out of bed. He does not wish to do things for himself. The family, at this point, do not help him. There are many days he does not even get dressed or if he is dressed, he doesn't get undressed and sleeps all night in his clothes. He has Medicare and Medicaid coverage. We feel here is a case where if Medicare and/or Medicaid covered our program, he would not have regressed to the point where eventually he will be placed in a long-term care setting for the rest of his life.

Case study 6

This was a 19 year old male with a diagnosis of Guillian-Barre Syndrome. He had complete quadriparesis with a tracheal tube due to respiratory problems. He reached a plateau of progress the beginning of November, 1976. Medicaid would no longer extend his stay as an inpatient in our acute setting for rehabilitation. It necessitated discharging him to a skilled nursing facility. At this time, he was still at a very completely dependent level. He could not feed himself. He could not turn or move in a bed. He was unable to push his wheelchair. He was unable to ring a bell for help. The care was very poor in the skilled nursing facility. No one took the time to feed him his complete meal which caused poor nutrition. No one came in to turn him at night to prevent bed pressure sores or toilet him when needed. Bathing was rarely done. He deteriorated from the level he had plateaued at. He, as well as his family, became very depressed and despondent and finally took him out of the skilled nursing facility. He was admitted to our Adult Day Health Treatment Center in November of 1976 after three weeks in the skilled nursing facility. We taught the family how to care for him at night. In our program, we carried out maintenance therapy, bathing, ongoing counseling to him and his parents, etc. After a couple of months, he started to show some very slight functional return, as is common in Guillian-Barre Syndrome, and could have been readmitted as an inpatient. We kept him in the day hospital level of our Adult Day Treatment Center and intensified his individual physical therapy and occupational therapy sessions, along with a group therapy session. This enabled him to be at home at night and on the weekends with his family.

He began using adaptive devices to independently feed himself. He started to be able to turn himself in bed and to maneuver his own wheelchair, and learned to transfer with help, utilizing a sliding board, from wheelchair to bed—wheelchair to car—wheelchair to toilet. Even though he had learned to use a universal cuff, he continued doing many things by holding objects in his mouth. He became so proficient at painting that he continued to do it by using his mouth rather than his hands. By September of 1977, he was ambulating independently with a walker, needing no assistive devices on his upper extremities to carry out functional tasks, and moved into independent living away from his family. In February of 1978, after receiving counseling on possible vocational/educational pursuits, he began attending a community college on a half-day basis. He attended classes on campus in the morning and continued to be a patient in our Adult Day Treatment Center in the afternoon where he continued to receive psycho-social services and intensive physical therapy, and now today is able to ambulate without any assistive devices. The cost of his care at the plateau level in our Adult Day Treatment Center was $323.40 a month versus the skilled nursing facility cost of $800.00 a month. The total cost of care in our Adult Day Treatment Center was $1,847 versus inpatient status total cost, which would have been $18,200. These costs covered the basic daily services and did not include the individual physical therapy and occupational therapy session costs. The Adult Day Treatment Center saved Medicaid over $16,000 on this one case. But, more important, we have rehabilitated the "Total Individual" and he is able to be at home as an active member of the family through his rehabilitation process.

In summary, the goals of our Adult Day Treatment Center are treatment-oriented, rehabilitative and restorative rather than custodial. Casa Colina Hospital consistently attempts to insure continuity of care for the disabled person, using the criteria of appropriateness of treatment modality. The orientation of the program is toward individualized treatment planning devised to appropriately meet the needs of the individual patient.

We have had to refuse many individuals who qualified for our Adult Day Treatment Center. They lacked private funds to afford it, and as a result have had to be placed in a long-term care facility. These individuals were all recipients of Medicare. Casa Colina Hospital is concerned that significant public and private resource is spent for institutionalization of disabled individuals. Our Adult Day Treatment Center is designed to serve all adults with disabling conditions, not just the elderly. We feel the time has come for the Federal Government and the Health, Education, and Welfare Department to develop the regulations and make Adult Day Health Services a permanent program reimbursable through Medicare funding.

Thank you for the opportunity to submit my testimony on Adult Day Health Care. I would like to extend an invitation to each of you, as members of the Select Committee on Aging, to visit our Adult Day Health Treatment Center at Casa Colina Hospital to personally observe and experience how Adult Day Health Care Services meet the needs of the chronically ill and elderly disabled.

casa colina hospital
for rehabilitative medicine

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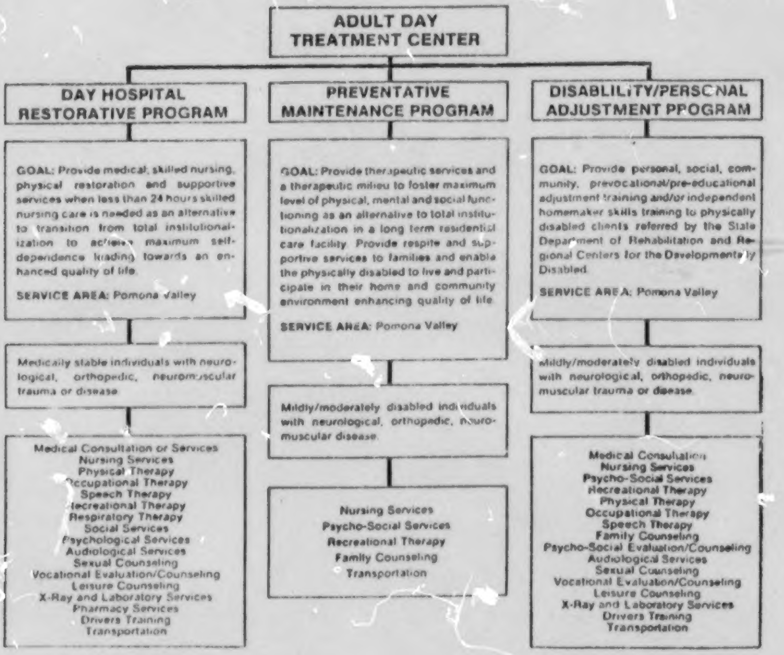

ADULT DAY TREATMENT CENTER

DAY HOSPITAL RESTORATIVE PROGRAM

GOAL: Provide medical, skilled nursing, physical restoration and supportive services when less than 24 hours skilled nursing care is needed as an alternative to transition from total institutionalization to achieve maximum self-dependence leading towards an enhanced quality of life.

SERVICE AREA: Pomona Valley

Medically stable individuals with neurological, orthopedic, neuromuscular trauma or disease.

Medical Consultation or Services
Nursing Services
Physical Therapy
Occupational Therapy
Speech Therapy
Recreational Therapy
Respiratory Therapy
Social Services
Psychological Services
Audiological Services
Sexual Counseling
Vocational Evaluation/Counseling
Leisure Counseling
X-Ray and Laboratory Services
Pharmacy Services
Drivers Training
Transportation

PREVENTATIVE MAINTENANCE PROGRAM

GOAL: Provide therapeutic services and a therapeutic milieu to foster maximum level of physical, mental and social functioning as an alternative to total institutionalization in a long term residential care facility. Provide respite and supportive services to families and enable the physically disabled to live and participate in their home and community environment enhancing quality of life.

SERVICE AREA: Pomona Valley

Mildly/moderately disabled individuals with neurological, orthopedic, neuromuscular disease.

Nursing Services
Psycho-Social Services
Recreational Therapy
Family Counseling
Transportation

DISABLILITY/PERSONAL ADJUSTMENT PROGRAM

GOAL: Provide personal, social, community, prevocational/pre-educational adjustment training and/or independent homemaker skills training to physically disabled clients referred by the State Department of Rehabilitation and Regional Centers for the Developmentally Disabled.

SERVICE AREA: Pomona Valley

Mildly/moderately disabled individuals with neurological, orthopedic, neuromuscular trauma or disease.

Medical Consultation
Nursing Services
Psycho-Social Services
Recreational Therapy
Physical Therapy
Occupational Therapy
Speech Therapy
Family Counseling
Psycho-Social Evaluation/Counseling
Audiological Services
Sexual Counseling
Vocational Evaluation/Counseling
Leisure Counseling
X-Ray and Laboratory Services
Drivers Training
Transportation

METROPOLITAN JEWISH GERIATRIC CENTER,
Brooklyn, N.Y., April 24, 1980.

Hon. CLAUDE PEPPER,
Chairman, Select Committee on Aging,
House of Representatives, Washington, D.C.

DEAR REPRESENTATIVE PEPPER: We are extremely pleased to be able to offer our comments and views on such an important and timely issue as Adult Daycare for health impaired older persons. We thank the committee for this opportunity.

Metropolitan Jewish Geriatric Center, with 915 beds, is one of the largest long term care institutions in the nation. In addition to SNF and ICF inpatient care, Metropolitan sponsors a Day Hospital, Long Term Home Health Care Program, Hospice, transportation services for the elderly and handicapped, Senior Center, and Institute for the Study of Aging & Long Term Care. The Day Hospital—a program aimed at providing long term health care and other support to chronically impaired older adults on an outpatient basis—was our Center's first effort to reach out beyond the four walls of the institutional setting to the population most at risk for placement in a nursing home.

Our Day Hospital began in October, 1977. Based on over two years of experience, we and the community we serve are convinced that the program and similar adult daycare projects make a valuable contribution to the quality of life of older people in the community. In our case, with the strong support of our Board and staff, the Day Hospital has managed to help maintain disabled older persons in their homes, make their lives more meaningful and productive, prevent or forestall their premature institutionalization, provide relief and support to their families, and offer an easy link to a whole range of needed services on the continuum of care.

The enclosed report, although prepared in 1978, presents a more detailed view of our program, including the many problems that had to be overcome in order to make daycare an acceptable and effective element in the community's long term care system. Many of these issues will have to be addressed by your Committee in its deliberations.

We had the opportunity to appear before Representative Waxman and the Subcommittee on health and the Environment in December, 1979 to discuss "Community-Based Long Term Care: Obstacles and Opportunities." In our presentation on New York State's Long Term Home Health Care Program, we urged the Congress not only to consider in-home care, but also the whole range of other non-institutional services that should comprise the comprehensive continuum. This, of course, includes Adult Daycare. Needless to say, we were pleased to see the Medicaid Community Care Act of 1980 as the outcome of this hearing. The inclusion of Adult Daycare as one of the covered services in the bill was particularly encouraging.

While we feel the Medicaid Community Care Act and the inclusion of the daycare option is a step in the right direction, we trust that your Committee will consider the following:

Incorporate Adult Daycare and other community-based long term care modalities into the Medicare benefit package.

Allow states participating in the Medicaid program the option of providing coverage for Adult Daycare services for certain low-income aged, blind and disabled people who need such care on a continuing basis to prevent or delay institutional placement, but are not categorically eligible because their incomes exceed the assistance standard.

In addition, we urge you and your Committee to use its influence in developing a visible, high-level, fully-staffed and funded unit within the Department of Health and Human Services to focus on the creation of community-based models, including mechanisms on the Federal, state and local levels to coordinate elements in the continuum of long term care.

Thank you for your consideration.

Respectfully,

DENNIS L. KODNER,
Director, Planning and Community Services.

THE DAY HOSPITAL AT MJGC: COMMUNITY TREATMENT SERVICES FOR CHRONICALLY ILL AND DISABLED OLDER ADULTS

(By Dennis Kodner, Program Director)

THE FIRST NINE MONTHS

Preface

Metropolitan Jewish Geriatric Center has long been concerned with the needs of older adults. The Institution's experience with delivering services to older New Yorkers convinced the Board of Directors and Administration that the dependent elderly perfer to remain in their own homes and, that for many aged persons, this would be possible if an effective interface between inpatient care and the community could be developed. In 1977, some ten years from the idea's conception, MJGC opened its Day Hospital to Brooklyn residents.

In recognition that the Center's Day Hospital is one of only a handful of such geriatric daycare programs in the metropolitan area, and that there still is a substantial unmet need for this health service among the many vulnerable, non-institutionalized elderly, MJGC—through its new Institute for the Study of Aging and Long Term Care—decided to sponsor a one-day conference on October 19, 1978 entitled, "Daycare for Impaired Older Adults: Philosophy, Planning and Practice." The purpose of the conference is to explore the daycare concept and the "real-life" experiences of MJGC, with a view to encouraging new project in this vital field.

This report, a detailed overview of the Center's program and its first nine months of operation, is a background paper to be used by conference participants. It will also be useful to other administrators, researchers, planners and policy-makers interested in the modality's potential and how it can be implemented.

ACKNOWLEDGMENTS

Particular credit is due to Mr. Eli S. Feldman, MJGC's Executive Director, and the following staff of the Day Hospital, who provided advice and assistance in the preparation of this report when help was needed: Linda DeVito, Liliane Droyan, Doris Simon and Kay Vanterpool.

A special word of thanks to the Board of Directors and Mr. Moses Wachs, MJGC's former Executive Director, for their encouragement and support. Without their strong commitment to the Program, there would have been no Day Hospital.

MJGC: An overview

Established in 1907 as the Brooklyn Hebrew Home and Hospital for the Aged, MJGC is widely known as a center of excellence for the innovative treatment, rehabilitation and care of the chronically ill, physically disabled and dependent older adult. The 915-bed, JCAH-accredited multi-level geriatric institution is operated under voluntary, non-profit auspices and is a member agency of the Federation of Jewish Philanthropies. The Center consists of skilled nursing and intermediate care facilities, Day Hospital and Senior Center, and is acknowledged as one of the largest and most advanced continuing health care facilities in the nation.

With the successful establishment of the Day Hospital, MJGC has entered a new era of outreach and service to the community. Energetic and creative efforts are being turned toward the development of a comprehensive range of intramural and extramural services—using the facility as the delivery core—aimed at keeping the elderly in the community for as long as possible as well as ensuring them an appropriate place on the continuum of care. An ambitious five-year master plan commits MJGC to strengthening its role in the fields of aging and long-term care by creating a Long Term Home Health Care Program under New York's "Lombardi Law," developing community-based home help services, establishing a Gero-Rehabilitation Institute and Hospice program and further supporting the educational and research activities of the new Institute for the Study of Aging and Long Term Care.

Evolution of the day hospital

MJGC's Day Hospital is a natural outgrowth of the Institution's long-term involvement in delivering services to older New Yorkers. Although the Day Hospital received licensing approval from the State Department of Health in June 1977 and opened its doors to the first registrant in October of that year, the program's actual conceptualization and planning can be traced back to the early part of the century when MJGC began to expand the scope of its services beyond those traditionally offered by a home for the aged. The Center recognized early that the unique needs of the elderly demand fresh approaches as well as new and improved programs. In 1918, MJGC became the country's first geriatric facility to open a hospital unit to provide a full range of medical and surgical services to its infirm residents. In 1953, the Institution became the first in New York City to house a Senior Center to provide older adults living in the community with meaningful recreational, educational and socialization opportunities. This was followed in 1975 by a "Meals-on-Wheels" program operated in conjunction with a community organization to provide nutritious meals to frail and home-bound older people, MJGC's experience with these and other programs convinced the Board of Directors and administration that older adults—if given a choice—prefer to remain at home among family and friends and that an alternative/forestaller to institutionalization—an effective interface between inpatient care and the community—was required. This feeling, coupled with the fact that at the time the Center had the highest occupancy rate of any Skilled Nursing or Extended Care Facility in New York State, compelled MJGC to pursue the idea of geriatric daycare.

Between 1968 and 1972, the daycare concept was further explored and incorporated into plans for the Center's new Brenner Pavilion; the State-financed building included space for the program. Eventually the idea was formalized and the Board elected to develop this outpatient program as a means of offering impaired older adults who do not require 24-hour custodial care access to supportive health and social services without forcing them to become institutionalized. In 1975, one year from the completion of the new building and after undertaking an evaluation of the unmet health needs of the chronically ill aged in the facility's service area and a survey of community resources, MJGC formally applied to the Health Department for approval to provide "Non-Resident Services" under Subchapter H (now Subchapter C) of the State Hospital Code. With assurances from the planning and regulatory bodies that the project would be approved, a Planning Task Force, consisting of department heads at the Brenner Pavilion, was organized to develop detailed program plans for the new service. Developing a geriatric daycare center as part of an inpatient unit involved many different considerations, including space, equipment, staffing and programming. The group met for six months to deal with each of these issues and, after finishing its work, was disbanded.

This paper addresses itself to the Day Hospital's first nine months of operation and provides a detailed profile of the program and its registrants during the period.

Program objectives

The concept of a Day Hospital at Metropolitan Jewish Geriatric Center was implemented to fulfill the following institutional and community service objectives:

1. To provide an integrated long-term program of health care and supportive services on an outpatient basis to aged persons who would otherwise deteriorate physically and mentally at home to a point where they would require 24-hour institutional care.
2. To serve as a short-term rehabilitation setting for older adults who cannot be adequately treated in a home care program or hospital outpatient department because of the need for a broader range of supportive services and socialization experiences to achieve optimum functioning.
3. To act as a medical-social halfway house for those older people who have been discharged from health care institutions and need time to develop sufficient self-care skills and emotional stability to permit continued independent life at home with a reasonable degree of self-satisfaction.
4. To provide relief to families caring for their disabled older relatives as a way to increase their support capabilities in sustaining them at home.

Administration and structure

The Day Hospital is covered under the Center's operating certificate, but is independently licensed as an established health service under subchapter C of the State Hospital Code. The Program itself is considered a department of MJGC's Brenner Pavilion and its Director is administratively responsible to the facility's Assistant Executive Director in charge of professional services.

The staffing and programming component of MJGC's Day Hospital reflects the uniqueness of the institutionally-based geriatric daycare center. The institution's administrative core is used as resource for billing, purchasing, payroll, administration and certain patient care and supportive services, including meals. The day-to-day conduct of the program rests in the hands of a full-time R.N.-Director, secretary and part-time clerk-typist. A full-time Nurses Aide and Orderly, Social Worker, Occupational Therapy Assistant and Physical Therapist are permanently assigned to the program from their respective departments. The facility's Activities Therapy Department integrates Day Hospital registrants into most of its inpatient programming. The Center's Speech Therapist, Respiratory Therapist and Dietary staff provide services on an as-needed basis and the Medical Department's diagnostic and treatment services are made available to registrants as well.

Admission and discharge criteria—intake process—patient care planning

The Day Hospital's target population is defined by broad admission criteria which have been applied to applicant selection since the program's inception. Registrants must: be 55 years old or more; live within a 10-mile radius of the Brenner Pavilion—in Kings County—and be able to cope with the day-to-day stress of commuting to the program; have a medical problem or disability; need therapy to improve, restore or maintain existing functions; need preventive, diagnostic or therapeutic services not feasible at home; need daytime supervision; be oriented to time, place and interpersonal functions; have a family or significant other person who requires relief in on-going patient care management; not require 24-hour institutional care.

Registrants can be discharged for a number of reasons:

1. It is determined that daycare is no longer needed.
2. The registrant requires a higher or more intensive level of care.
3. The program does not meet patient expectations.
4. Continuation in the Day Hospital is considered inappropriate because of patient adaptation problems.
5. Excessive absences, including prolonged hospitalization.
6. Relocation out of service area.
7. Death.

The intake procedure has many steps. First is the initial inquiry about the program by the elderly person, a relative, a professional on behalf of the applicant or some other significant person. This is routinely handled by the Day Hospital secretary and/or Social Worker, depending on the nature of the questions. This may or may not lead to the second stage, wherein applicants receive a two-part application. The first part contains identifying data and detailed social and financial information to be furnished by the registrant or responsible family member. The second part, a medical report, is completed by the applicant's personal physician or referring hospital. Once these materials are received, the entire admissions file is screened by the R.N.-Director and reviewed by the program's Social Worker. Telephone interviews with the applicant, his family or physician are used when certain information is missing or incomplete. If appropriate, the applicant and family members are invited for a pre-admission interview and evaluation session which can last from one hour to one and one-half hours. This provides a face-to-face opportunity to make a fairly comprehensive assessment of the applicant's needs and the appropriateness of the service as well as to explain the treatment program and answer any further questions. The meeting also provides some time for the patient to view the on-going program and meet other registrants and key staff. If an applicant has no means of transportation to the Center, a home visit by the Social Worker will be arranged in lieu of the personal interview on the premises of the Day Hospital. The final stage of the intake process is a formal interdisciplinary evaluation by the R.N.-Director and Social Worker to determine admissability. The applicant and his family are advised of the final intake decision once it is reached. If acceptable, the registrant is advised of the number of days per week he will be coming and the actual date he will begin. The applicant is also asked to sign the actual date he will begin. The applicant is also asked to sign a standard patient care agreement required by State regulations. From the applicant's initial inquiry to the first day in the program, the entire intake process takes about one month. For registrants who are referred by hospital outpatient departments, intake can take as little as two to three weeks, because the medical portion of the application is usually easier to obtain.

Depending on the number of days per week a registrant is scheduled to attend the Day Hospital, a patient care plan is developed in the person's first or second week of the program. Additional members of the interdisciplinary team (Activities Therapist, Dietician, Occupational Therapists, Physical Therapist and, if needed, a Speech Therapist) further assess the patient and develop appropriate goals. The facility's Medical Director or Chief Medical Staff takes a medical history and performs a thorough physical examination on the patient's first day. The personal physician or referring hospital is then advised that the patient is in the program. A copy of the patient care plan is forwarded along with this notification for the doctor's signature, if the registrant is covered under Part B Medicare for any portion of the treatment plan. The personal physician also receives a progress report on his patient from the Day Hospital every two months.

All registrants are reassessed by the Social Worker every sixty days to determine the continued need for Day Hospital services and to modify or amend the patient care plan as needed. The entire patient care team and personal physical/referring hospital are involved as in the initial patient care planning stages.

Range and scope of services

The range and scope of services provided within the Day Hospital program include the following:

Activities therapy.—Older adults are often unprepared to cope with leisure time. The Activities Therapy Program at MJGC provides companionship and fun, a sense of belonging, a feeling of contentment, an opportunity to receive recognition, an occasion for new learning and a way to replace declining health and functioning with more efficient use of remaining skills and capacities. Activities for Day Hospital registrants include: arts and crafts, cooking, dance, exercise, singing, special events (birthdays, holidays, etc.) and discussions. Programs are designed to meet the individual and group needs of registrants.

Medical services.—All registrants are under the care of their family physician or hospital Outpatient Department. On-site medical care includes taking histories and performing physicals of newly admitted patients; rendering first aid when registrants are involved in accidents or medical emergencies at the Center; and, evaluating acute episodes of illness. When certain specialty diagnosis or treatment is required and is not available for one reason or another in the community, they may be provided by one or more of the Center's clinics. This includes Dentistry, ENT, EKG, Gynecology, Podiatry, Psychiatry, Ophthalmology, Optometry, Urology and X-Ray.

Nursing services.—Health care surveilliance, triage, personal care and patient care coordination are major parts of the Day Hospital's basic service to all registrants.

Occupational therapy.—OT can be functional or diversional in nature and is designed to increase range of motion, strength, dexterity and coordination.

Physical therapy.—PT is provided using such modalities as exercises, heat, cold, whirlpool, ultrasound and diathermy in areas of ambulation, gait training, transferring techniques, assistance with prosthetic devices, maintenance of joint motion and prevention of disability from degenerative joint diseases. Individual and group treatments are used.

Speech therapy. For those who require it, speech therapy is provided as part of the patient care program.

Respiratory therapy.—This is an integral part of the program for patients in need of the service.

Food service and nutritional counseling.—A hot midday meal and morning and afternoon snacks are provided by MJGC's inpatient Food Service Department. Meals are brought to the Day Hospital in a tray carrier. Nutritional consultation is provided by members of the Dietary staff and the R.N.-Director. This service is also provided to family members in order to help them to implement a planned dietary program at home.

Self care education and training.—This is an on-going part of the Day Hospital program which occurs within the Center or in the patient's home. Registrants are taught to recognize medical illnesses, comply with treatment regimens and learn homemaking and ADL skills. The entire treatment team is involved in providing this service.

Spiritual counseling.—MJGC's spritual advisor, a Rabbi, provides counseling for those registrants who want it. Chaplains of the two other major faiths are also available to Day Hospital patients.

Community outreach.—This is an essential ingredient of the Day Hospital. Both the R.N.-Director and Social Worker have been involved from the outset in educating professionals and consumers in the community about the program's existence and purpose. Next, contact was made with agencies and institutions in the service area to locate and reach the target population. As a result, an extensive referral network has been developed and the program is widely known. This continues to be an important activity of MJGC's administration and the Day Hospital staff.

Transportation.—This service connects patients living in the community with the services of the Day Hospital. It is, therefore, an essential component of the program. Some registrants are transported by family members. Others are brought by ambulette through a commercial vendor or private care service.

Volunteers.—These community minded people perform special services within the Day Hospital setting and are usually assigned to and supervised by a team member. Trained volunteers are especially helpful in creating and sustaining a bright, positive atmosphere for Day Hospital registrants.

The Day Hospital's patient care program operates from 9 A.M. to 3:30 P.M. daily, five days a week. A typical daily schedule of a registratnt is as follows:

Time	*Activity*
8:40 to 9:00 A.M.	Arrival and coffee/juice.
9:15 to 10:00 A.M.	Physical therapy.
10:15 to 10:40 A.M.	Discussion group.
10:45 to 11:15 A.M.	Exercises.
11:15 to 12:00 noon	Medications and necessary medical treatment.
12:00 to 1:00 A.M.	Lunch.
1:00 to 1:30 P.M.	Rest period.
1:30 to 2:30 P.M.	*Scheduled activity (arts and crafts, cooking, birthdays, group discussions, etc.).*
2:30 to 3:00 P.M.	Snacks.
3:00 to 3:15 P.M.	Prepare to leave.
3:15 to 3:30 P.M.	Departure.

Physical facilities

The Day Hospital occupies part of the Brenner Pavilion's Medical Facility Unit. The building's fourth floor consists of 25,000 square feet of clinic space and patient treatment areas. The area strictly devoted to the Day Hospital comprises three rooms—Day Room and offices, Television Room, and Lounge—occupying 1066 square feet of space, or slightly less than 5 percent of the floor's total area.

With more than twenty registrants on an average day, the present area is too cramped to accommodate daily programs and office activities at the same time. Therefore, we are currently considering the relocation of the Day Hospital's offices to other areas on the fourth floor.

Registrant characteristics

Day Hospital registrants range in age from 51 to 93 years, with 70 percent over 70. The mean age was slightly less than 76 years. Nineteen percent are male and eight-one percent are female. Ninety-seven percent are white and eighty-seven percent are Jewish. Seventy-five percent are single, widowed, separated or divorced.

Forty-nine percent live alone in their own apartments. Thirty-eight percent live in their own apartments with either a spouse, relative/non-relative, and the remaining thirteen percent live in the households of their children, other relatives/non-relatives or senior citizen hotels, DCFs, etc.

Almost 42 percent of the Day Hospital registrants live within a one to five mile radius of the Center. Thirty percent live a mile or less away. Twenty-eight percent live five to ten miles from the program.

Diseases of the circulatory system account for fifty-one percent of the primary diagnoses of registrants on admission to the Day Hospital. Twenty-two percent have diseases of the central nervous system, musculoskeletal system and fractures; nine percent malignant neoplasms; ten percent diabetes and eight percent have miscellaneous other diagnoses.

Based on the predictor scores obtained on New York State's Long Term Care Placement Form (DMS-1) 94 percent of the registrants qualify for some level of residential health care (i.e., SNF or HRF) on admission to the Day Hospital. With a mean predictor score of 119.2, 76 percent of the registrants qualify for HRF care and 18 percent for SNF care. DMS-1 scores ranged from 41 to 363.

Some 58 percent of the registrants walk with aids and 16 percent use wheelchairs; 27 percent walk without assistance.

On admission, 98 percent of the registrants had their own physician or were regularly receiving medical care at a hospital Outpatient Department.

Information and referral sources

Referrals for patients accepted by the Day Hospital come from many sources: 40 percent from family and friends; 22 percent from hospitals; 20 percent from social service agencies and other community organizations; 10 percent from the applicants themselves, and 8 percent from MJGC and other residential health care facilities.

In analyzing where registrants obtained their information about the Day Hospital, 27 percent learned about the program from social service agencies and other community organizations; 24 percent from a hospital Social Service Department/Discharge Planner; 19 percent from advertisements; 12 percent from MJGC and other residential health care facilities, and 9 percent from articles in daily and community newspapers.

Utilization

Between October 1, 1977 and June 30, 1978—nine full months of operation—the Day Hospital had admitted 67 persons; 22 had been discharged; 45 remained at the end of the period. The Day Hospital averaged seven admissions and two discharges per month. During this period, 22 percent of the registrants attended once weekly, 54 percent twice weekly, 22 percent three times weekly, and 2 percent five times weekly. The average length of stay, counting the total time lapsed from the day of admission to either the day of discharge or the last day in the study period, is almost 94 days. Twenty-four percent were in the program for over six months; 23 percent for less than a month; 42 percent from 1-3 months, and 15 percent from 3-6 months.

Almost 54 percent of the registrants made at least one visit to a diagnostic or special care clinic at MJGC. A total of 123 visits were reported. Ophthalmology and Optometry accounted for 42 percent of these visits; Podiatry, 30 percent; Dentistry, 9 percent; Psychiatry, 9 percent; ENT, 8 percent; and, EKG, 2 percent.

Almost 67 percent of Day Hospital registrants attended Physical Therapy; 33 percent, Occupational Therapy; 10 percent, Speech Therapy; and 5 percent, Respiratory Therapy. Obviously, many registrants visited more than one Rehabilitation service at MJGC. A total of 1521 visits were recorded during the nine month period. On the average, each person made 20.5 visits to PT; 16.5 visits to OT; 20.4 visits to Speech Therapy, and 23.7 visits to Respiratory Therapy.

While early data does not tend to support the expected relationship between DMS-1 scores and the number of visits to rehabilitation therapies, statistics obtained recently clearly show a strong connection between the two. This discrepency can probably be best explained by a combination of factors: the tightening of rehabilitation need criteria for Day Hospital registrants, greater admissions selectively, and the increasing conflict between inpatient and Day Hospital rehabilitation programming and scheduling.

Reimbursement

The primary source of reimbursement for Day Hospital patients was as follows:

	Percent
Medicaid	75
Self pay (includes self pay/medicare; and, self pay/sliding scale)	23

	Percent
Medicare (includes medicare/medicaid; medicare/private insurance; and, medicare/self pay)	1
Other third parties	1

Medicaid reimburses MJGC $23.95 per patient day for day Hospital care.

Transportation

Transportation is critical to the success of a geriatric daycare program. Yet it presents the greatest amount of frustration and is one of the most expensive components. Almost 95 percent of Day Hospital registrants use some form of vehicle transport to and from the Center; 5 percent walk from home. Fifty percent are transported by ambulette, fourty percent by taxi/limousine and five percent by family automobile.

Medicaid reimburses the commercial vendor directly at the established rate of $32 round trip. Registrants who are not covered by Medicaid pay these carriers a discounted, but still high fee. In order to reduce this heavy financial burden, MJGC applied for and recently received a Federal matching grant under UMTA 16(b)(2) program to purchase specially equipped vehicles to transport Day Hospital registrants at a nominal fee. This service will commence late next summer.

Conclusion and summary

The MJGC experience highlights important aspects of the planning, development and operation of a daycare program within the context of a geriatric institution. The institutional setting has had a clear impact on the delivery of these services to the community and vice versa.

The philosophy of the sponsoring institution, MJGC, has greatly influenced the Day Hospital's service orientation. Geriatric daycare can either focus on rehabilitation or maintenance; the Day Hospital is aimed, by and large, at increasing the functional level of older adults. The type and combination of health and supportive services, was, therefore not only based on the needs of the population-at-risk, but also determined by the scope of institutionally-based resources potentially available to the new program. The Day Hospital and its apparent success has had a beneficial effect on MJGC. The traditional image of the facility as an "old age home" has given way to local and national recognition as a Comprehensive Geriatric Center and an enhanced reputation as an innovator in the fields of aging and long term care. Integration between MJGC and the surrounding communities has increased tremendously. The program's innauguration has also sparked the beginning of a new era of outreach and community service for the institution. The Day Hospital is viewed by the Board of Directors and administration as only the first step in a series of contemplated programs to keep older people in their homes and out of residential health care facilities.

On the other hand, the Day Hospital has presented some difficult problems for the institution. It has taxed the leadership abilities of the administration and has forced the facility into an on-going conflict over scarce institutional resources between the program needs of residents/inpatients and Day Hospital registrants. From an operational point of view, the high rate of absenteeism among registrants necessitates almost daily rescheduling of therapy and clinic services, and Medicaid policies and procedures require a vast amount of time-consuming paper work which could otherwise be directed to direct patient care.

The vital aspects of transportation, referrals, and financing represent the three other major dilemmas for the program. A geriatric daycare program is not really viable without a solid transportation system. The coordination of this service, its high cost, the lengthy travel time for many persons, and the uneven quality are frustrating to the Day Hospital registrants and staff and present a great challenge. Developing needed referral sources presented an early obstacle, although it is the program's lifeblood. While the program now has a waiting list, it took many months and a lot of time and hard work. This was, in part, due to MJGC's relative inexperience in the community service field. More importantly, however, the marketing of the program proved far more difficult than initially expected. Many private physicians and hospitals considered the Day Hospital a direct competitor for their patients. Senior Citizen Centers felt the same way about the role the program could play with their clients. An intensive educational program and constant reminders of the responsibilities of these professionals and agencies to the aged helped to overcome much of this early confusion and opposition. With respect to financing, non-Medicaid eligible older adults and their families find it difficult, it not impossible , to afford the full cost of the program and non-subsidized transportation. While MJGC has provided financial assistance to many registrants from community funds in the form of a sliding scale fee, the financial burden for the institution is considerable. More importantly, the present Medicaid reimbursement, pegged by the State to one/third the facility's inpatient rate, is unrealistic and severely underestimates the true cost of providing the Day Hospital's intensive matrix of services.

The Day Hospital at MJGC—despite some formidable problems—provides a valuable service to impaired older adults living in the community. With the strong support and encouragement of the institution's Board, administration and staff, as well as the program's growing acceptance among consumers and providers, the Day Hospital has managed in less than a year's time to help maintain disabled older people in their homes, make their lives more meaningful and productive, prevent or forestall their premature institutionalization, provide relief and support to their families, and offer an easy link to a whole range of needed services on the continuum of care.

The American Occupational Therapy Association, Inc.,
Rockville, Md., May 9, 1980.

Hon. Claude D. Pepper,
Chairman, Select Committee on Aging,
Washington, D.C.

Dear Chairman Pepper: I am enclosing the statement of The American Occupational Therapy Association in conjunction with your Committee's hearings on adult day care centers. I request that this statement be included in the record of the hearings.

The Association applauds the Committee's initiatives regarding this very important area of service delivery. We believe adult day centers have much to offer our Nation's older citizens.

We look forward to working with you as you seek to improve these programs, and we offer whatever assistance we can provide.

Sincerely,

Francis J. Mallon,
Director, Government and Legal Affairs Division.

Statement of the American Occupational Therapy Association

The American Occupational Therapy Association (AOTA) founded in 1917, now represents close to 29,000 occupational therapists, occupational therapy assistants and students nationwide. The health professionals represented by the AOTA specialize in increasing the independent functioning and productivity of people of all ages who are physically, psychologically, or developmentally disabled.

Occupational therapists work in a wide variety of settings using rehabilitation techniques to reduce pathology or impairment and help their clients achieve a maximal level of independence. Occupational therapists are committed to the belief that a health system which provides the best medical intervention in the world to save a life is incomplete if it does not include services to help ensure that the life which has been saved will be meaningful and productive.

A significant proportion of occupational therapists and occupational therapy assistants—approximately one-third work with individuals over 65 years of age. Occupational therapists are intimately involved in providing health care services to older people both in institutional settings, such as hospitals and nursing homes, and through community based facilities and organizations, such as health centers, home health agencies, and day care centers. Occupational therapists, therefore, are especially supportive of efforts to improve the health care provided to the country's older population and the commend the Committee for initiating congressional discussion of the role of adult day care centers in such efforts. Occupational therapists have a long history of involvement in adult day care services. Consequently, they have developed a deep understanding and commitment to the value of adult day care in assisting individuals to maintain their independence and sustain themselves in the community.

Adult day care was initially developed in Europe and is an established part of the European and British health care system. The earliest adult day care models were termed Geriatric Day Hospitals which developed out of occupational therapy departments housed in general hospitals. The treatment program emphasized training in activities of daily living, and selected craft activities designed for both groups and individuals. Physical therapy, social activities and assessments of social competence were also part of the program. The full time staff of the day hospital was comprised primarily of occupational therapists and orderlies, with clerical services and part-time physical therapy, speech therapy, social work and medical supervision available from the main hospital.

In the United States, adult day care is a relatively new concept. In 1974 only six programs were in existence. Since then over 600 programs have been established. The interest and involvement in adult day care have evolved primarily at the community level with substantial support from both public and private sources.

A guiding principle of the occupational therapist working in the adult day care setting is that purposeful activity, or occupation, including its interpersonal and environmental components, may be used to prevent and mediate dysfunction and to elicit maximum adaptation. At the geriatric phase of the human developmental continuum the need for adaptation increases as the functional capacities of the human system begin to decrease. Adaptation is a change in function that promotes survival and self-actualization. When a person fails to adapt, dysfunction frequently occurs, and the individual becomes dependent upon external resources. The occupational therapist uses purposeful activity, that is, occupation which is appropriate for a given older person, to facilitate the adaptive process, thereby improving functional performance and the client's ability to remain in the community.

Frequently, adult day care centers are categorized as emphasizing a social/health maintenance or a medical model. Although the overall care provided in both types of programs is part of the continuum, the status of the majority of individuals being served occasions the differences in emphasis. Occupational therapists, together with several other health professionals, work in both models.

Social/health maintenance model

As a part of the multidisciplinary team, the occupational therapist serves either as a planner-administrator-program coordinator or as staff member or consultant.

As a planner and administrator the occupational therapist is involved in developing adult day care for a given area or community. Using knowledge of behavior and activity as it concerns the frail, at-risk, older population, the occupational therapist plans a program which meets both the needs of the client population and those of the larger community. This involves working cooperatively during the planning and formative stages with the professional staff of other service delivery agencies to assure appropriate coordination and maximum use of existing services. In this role, the occupational therapist must evaluate the community and determine the proper initial program focus, which might be directed towards social services, health maintenance and prevention, medical issues, or some combination of these. The occupational therapy frame of reference assures that client, family, and staff concerns regarding environment, activity, socialization, and physical and psychological functioning will be addressed in the planning stages.

Concern for these same issues will be carried over into the occupational therapist's role as administrator and/or program coordinator. Since occupational therapy reinforces and supports the concerns of all team members, including the client and family, it acts as a unifying force and encourages effective implementation of a dynamic program and individualized plan of care.

The occupational therapist, as staff member, evaluates clients considered for placement in the day care center in order to identify their existing degree of functional capacity. The client's ability is evaluated in the three major areas of occupation: self-maintenance or self care, productivity or work, and leisure or play. The therapist assesses the client's occupational performance according to the functional components of motor, sensory, cognitive, and intrapersonal and interpersonal skills. Following these evaluations, treatment programs are designed to achieve the three major goals of occupational therapy intervention:

1. The reduction of deficits in occupational performance.
2. The elimination of barriers to occupational performance.
3. The nurturing of competency in occupational performance.

Many of the clients referred for a social-health maintenance model of day care do not demonstrate severe deficits in occupational performance. Usually their problems are confined to subtle losses in sensory and motor systems, physical endurance and function, and cognitive and socialization skills. An initial evaluation enables the occupational therapist to identify specific problem areas and design a plan of treatment which is then incorporated into the team's plan of care. Generally, these clients do not require an intensive, long term occupational therapy treatment program, but only short term treatment intervention. The occupational therapist may also serve as a consultant to the other team members and assist them in implementing appropriate treatment designed to improve occupational performance.

Many individuals in these settings have minimal sensory, motor and cognitive deficits which prevent successful integration of the new information which is usually a part of the center's daily activity program. These same clients tend to be awkward and clumsy in their movements, thereby presenting difficulties at mealtime or when participating in an activity session. They may also demonstrate a short attention span, diminished self-esteem, emotional lability, low frustration tolerance, and poor peer interaction. The occupational therapist, working cooperatively with the team will identify specific, meaningful tasks for the client. These tasks will be structured, sequenced and appropriately adapted to address the individual's particular problems.

During the short term occupational therapy treatment phase, the therapist will help the client develop a secure functional baseline, so that he can adapt to, cope with, and, hopefully, overcome the deficits identified. In treatment, this may require reinforcing new information by sequencing specific activities involving the motor, visual, tactile, kinesthetic and other sensory systems in addition to the cognitive system. Environmental adaptations involving, for example, physical positioning are also introduced. These approaches are reinforced by the total team in the center's daily activities program. As the client's baseline functional performance improves, the need for treatment diminishes and the daily program structure is modified to meet the client's individual needs. At this point, the therapist assumes the role of consultant, periodically reviewing progress and routinely assisting staff and client with specific problems as they arise.

As a consultant, the occupational therapist assists staff to develop specific group and individual programs which may be necessary to maintain the client's functional level and/or prevent further deterioration. Group homemaking and feeding and cooking programs, involving specific structure, placement, positioning and adaptive equipment, can enhance client performance while at the same time contributing to increased self-esteem and socialization. Work oriented activities, for example, use of an assembly line or specific task assignment system, similarly require occupational therapy input to help identify and develop appropriate procedures and methodolgy which will hasten client improvement. Enhancing the client's daily life skills, whether in the area of personal self care or general self maintenance in the community, can also be implemented on an individual or group basis.

The occupational therapist is availalble to assure the development of specific procedures and approaches necessary to meet the needs of the particular clientele being served. The therapist is also used as an expert resource to client and staff when management problems arise concerning independent life skill performance. In some centers, the certified occupational therapy assistment may also be a part of the full time staff, functioning as program or activity coordinator.

Medical model

The role of occupational therapy in a medical based day care program differs somewhat from the social/health maintenance model. Essentially the difference is one of degree and duration. In most medical model settings, clients will require an extensive and intensive restorative treatment program. These clients usually demonstrate major deficits in functional performance, putting them much closer to the "risk of institutionalization" level of care. Once evaluated, clients may be placed on a specific treatment program of greater intensity than that required by social/health maintenance participants. The occupational therapist works closely with all other team members, as well as with the client and family to assure appropriate integration and carryover of the established team plan and goals.

Consider, for example, the situation of a client who has had a stroke causing sensory loss of the left arm and visual impairment on the left side demonstrated by a left sided neglect. Typically, family and staff report that the client is constantly bumping into things, that he refuses to use his left arm, even though he can move it and has been observed using it. The arm is bruised, or may have had a recent burn, which was ignored by the client. The occupational therapy evaluation indicates perceptual problems, most significantly a left hemianopsia; deficits on the left side in proprioception, kinesthesia, sterognosis, and in touch, temperature, and sensation. The client is easily frustrated, very labile, and while fairly independent in a wheelchair is moderately dependent in his personal self care.

The occupational therapy treatment for this individual will focus on sensorimotor treatment to help the client reintegrate the two sides of his body. Training in activities of daily living is implemented in conjuction with the day care nursing staff, who emphasize particular techniques and approaches outlined by the occupational therapist to help the client increase awareness of his left side, as he performs dressing and grooming tasks. Specific compensatory techniques are taught to help the client overcome his left field deficit, and these are incorporated into the day care staff plan of care.

In this situation the occupational therapist would also work very closely with the activities coordinator to assure that these compensatory techniques are applied in the daily activity session. The social worker would work with the occupational therapist to help the family understand the problems and be supportive of the client's needs. The occupational therapist would also work with the family and client to modify and adapt the home to meet the needs of a wheelchair bound individual.

For both the social/maintenance and medical type programs occupational therapists support and encourage a multidisciplinary approach in the adult day care setting. The goal of promoting the client's continued survival in the community along with encouraging client self-actualization is shared by all disciplines. As part of the team, occupational therapists alert other members to client deficiencies in functional or adaptive occupational performance and work cooperatively in a team approach to facilitate client potential for continued and/or improved independence.

The American Occupational Therapy Association is aware that differing opinions on the effectiveness of adult day care treatment have been presented to the Committee. The Association's experience and information is much more in concert with the reports of the On Lok Day Health Centers in San Francisco, California and the Massachusetts Department of Public Welfare than with the assessments provided by William G. Weissert, Ph.D. of the National Center for Health Services and Research (Department of Health and Human Services.) Although the Association has not conducted surveys or studies in the adult day care area, reports from Association members indicate that significant benefits—related both to quality of care and cost effectivenss—derive from the treatment and services provided in adult day care centers.

The Association, therefore, fully supports the continuation and expansion of adult day care services. Furthermore, the Association urges Congress to provide support for comprehensive and in-depth studies of this form of service delivery. Such studies are necessary so that effective and appropriate support mechanisms, involving a cooperative and responsible mix of public and private resources, can be established. The Association further urges that the discussion of adult day care not get bogged down in unnecessary and wasteful distinctions between social and medical models. In this context, it is hoped that a major emphasis will be placed on development and maintenance of a continuum of care, whose goal is independent living, to whatever degree possible, and whose specifics are determined by the individual needs of the person being served. In this way the primary focus will be where it belongs—on each of the nation's older citizens.

The American Occupational Therapy Association appreciates the opportunity to offer these comments.

State of Florida,
Department of Health and Rehabilitative Services,
Tallahassee, Fla., April 16, 1980.

Congressman Claude Pepper,
Chairman, Select Committee on Aging, Subcommittee on Health and Long-Term Care, Washington, D.C.

Dear Congressman Pepper: In preparation for the April 23 Subcommittee hearing on adult day care, I am transmitting a recently completed issue paper on the addition of medical adult day care to the Florida Medicaid Program. A service proposal has been submitted to the Florida Legislature to implement the program by January 1, 1981.

I hope the issue paper will assist you and your staff's ongoing efforts to provide adequate services for our elderly citizens. If you have any questions, please do not hesitate to contact this office (904/488-1003).

Sincerely,

LuMarie Polivka-West,
Medicaid Program Specialist.

Attachment.

Chapter IV, Medical Adult Day Care

INTRODUCTION

Since the advent of Medicare and Medicaid, national and state reimbursement policies have supported an institutional model of care for impaired adults in need of health services. As a result, 70 percent of the 16.3 billion Medicaid budget in 1977 went for institutional care nationally, whereas 78 percent of Florida's 1977 Medicaid budget supported institutional health care of the categorically needy. As a result of this institutional care bias, nursing homes for long term care of the elderly have flourished, whereas non-institutional care facilities for the elderly in need of ongoing health services have been developed by the State primarily on a research and demonstration project basis.

The Florida Legislature enacted the Community Care for the Elderly Act in 1976. The law required HRS to implement and evaluate four different kinds of community care programs: home delivered care, family placement, senior center care and adult day care. The Florida Legislature required a specific evaluation of adult day care programs. In addition, it required that community care services "when possible shall be obtained under . . . the Florida Plan for medical assistance under Title XIX of the Social Security Plan". The evaluation results will be discussed in a later section.

The Florida Medicaid Program does not currently provide reimbursement for medically oriented adult day care. Although funding of adult day care programs is possible through a number of other Federal funding sources, including Title III of the Older Americans Act, Title XVIII and Title XX, very few adult day care programs have been developed in the State or funded by HRS.

HEW has approved Florida's 1115 Waiver application to waive a number of Title XIX rules and regulations in order to receive Title XIX funding of the Ancillary Community Care Services Project. In addition to other community care services, medically oriented adult day care will be funded in part by Title XIX funds for the first time. The five day treatment centers funded under the demonstration project will be medically-oriented and will provide services by medical professionals in addition to socially-oriented services. The Title XIX Medicaid Demonstration Grant will provide the medically-oriented, adult day treatment services to ninety-seven frail, elderly clients by the third project year. This is a small sample of the target group in need of such services. Therefore, a number of Medicaid eligible, primarily impaired elderly persons in need of services provided by a medically oriented adult day care program, may continue to be placed in institutional care unnecessarily because of the lack of appropriate community alternatives.

PROGRAM ISSUES

Given the increasing inflation in health care costs and the political and economic climate today, states are being compelled to seek the most effective uses of scarce health financing resources. One means is to minimize the use of expensive institutional and acute care health services and to maximize the use of less costly services such as outpatient and preventive care. Yet, as numerous studies have indicated, the cost/benefit results of institutional versus non-institutional care are dependent on such intervening variables as the level of skilled nursing care required by a service model, the impairment level of clients, the average daily attendance by facility, transportation costs and start-up costs.

It is a complex issue with no easy answers to the major program questions of whether medically oriented adult day care programs can (1) reduce institutionalization and promote deinstitutionalization, (2) improve or maintain physical and psychosocial functioning, and (3) be provided at a cost less than institutional care for comparably impaired elderly. If the evidence indicates that an adult day care program can positively address these program concerns, then it would be in the State's best interest to extend Medicaid funding to these programs statewide in order to increase the resource base for this type of community care alternative.

PROGRAM OBJECTIVES

The goal of medically oriented adult day care is to provide noninstitutional medical services to Medicaid eligible recipients who have chronic physical impairments which, in the absence of alternative services, would require nursing home placement. An elderly person is at risk of institutional or nursing home placement when one's ability to tend to personal health and daily maintenance needs are inadequate to compensate for a physical or mental disability.

Chronic health problems are common among the elderly and consequently medically oriented adult day care does not consist exclusively of restorative and rehabilitative services. There is also a specific program objective to provide preventive and maintenance health services intended to keep the characteristics of aging from unnecessarily debilitating an elderly person.

Additional program objectives are as follows:

Provide outpatient medical care, including medical maintenance, pharmaceutical services, crisis intervention, counseling support services and referral.

Develop and deliver services which will enable individuals to maintain living arrangements in the community which are suitable to individual needs, resources and preferences.

Link services with the needs identified in an individual care plan.

Perform a continual monitoring process of all individuals to ensure adequate and appropriate care.

BACKGROUND

The Social Security Amendments of 1972 (P.C. 92-603) required the Secretary of HEW to establish an experimental program of adult day care in order to evaluate the effect of this type of program on promoting alternatives to institutionalization and reducing the cost of providing nursing home care. HEW has funded a number of research and demonstration projects since that time to develop a medically oriented adult day care model. As a result of the evaluation of initial demonstrations, the Medical Services Administration of HEW published in 1976 an information memoranda on reimbursement under Title XIX for day hospital and day treatment services.

Since 1976, Title XIX funding has been available for day hospitals and day treatment services. The day hospital is distinguished from a day treatment service program by its greater emphasis on rehabilitation and restorative services and its closer relationship with a hospital or rehabilitation center. The day hospital offers many of the same services as a general hospital but eliminates the costly room and board services of a twenty-four hour facility. There are a number of basic services that can be offered in day hospital and a day treatment service program and which can be funded under a state's Title XIX progam including the following:

Medically Oriented Adult Day Care Services:

1. Medical services supervised by a physician, which emphasize diagnosis, treatment, prevention, rehabilitation, continuity of care, and maintenance of adequate medical records.
2. Nursing services rendered by professional nursing staff, under a nursing plan of care.
3. Diagnostic services including laboratory, X-ray, and related clinical services.
4. Rehabilitation services:
   (*a*) Physical therapy as prescribed by a physician, appropriate to meet the ambulatory needs of the patient;
   (*b*) Speech therapy for patients with speech language disorders;
   (*c*) Occupational therapy as an adjunct to treatment designed to restore impaired function of patients with physical and mental limitations;
   (*d*) Inhalation therapy for patients having chronic upper respiratory problems.
5. Pharmaceutical services with the responsibility for obtaining, storing, dispensing and administering medications.
6. Podiatric services provided or arranged for under direction of the supervising physician.
7. Optometric screening and advice for low-vision cases by a licensed ophthalmologist or optometrist.
8. Self-care services oriented toward Activities of Daily Living (ADL) and personal hygiene. This includes toileting, bathing, grooming, etc.
9. Dental consultation to assist patients in obtaining regular and emergency dental care.
10. Social services for patients and their families to help with personal family and adjustment problems which may interfere with effective treatment.
11. Recreational therapy to meet the psychological and social needs and interests of the patient.
12. Dietary services, with meals of suitable quality and adequate quantity to attain and maintain nutritional requirements, including special diets. Dietary counseling and nutrition education for the patient and his family is a necessary adjunct of this service.
13. Transportation service for patients to and from thier homes, utilizing specially equipped vehicles to accommodate patients with severe physical disabilities that limit their mobility.[1]

TARGET POPULATION

The target population for medically oriented adult day car consists of Medicaid eligible, chronically ill, elderly, or other disabled persons who meet one of the following criteria:

Are at the point of discharge from hospital or other acute facility and who, except for the availability of a "Day" program, would be placed in a long-term care institution;

Are residing in the community but are "in crisis" and imminently in danger of institutionalization. These are persons whose disabilities and level of functioning are such that without intervention, institutional placement would likely occur;

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[1] Information Memorandum, SRD-IM-76-3 (MSA), January 22, 1976.

Are residents of nursing homes or other long-term care facilities, but for whom institutional placement is determined to be unnecessary, and are judged to be appropriate candidates for a "Day" program.

PROGRAM BENEFITS AND LIMITATIONS

Medically oriented adult day care is suited for elderly clients with one or more diseases or disabilities which are either painful or which require substantial medical treatment. The major program benefit is that adult day care makes it possible for a proportion of these physically impaired elderly to remain in the community. The following quote from a preliminary report prepared by the Miami Jewish Home and Hospital for the Aged Adult Day Care staff helps put this program benefit in perspective: "Eighty-eight of the current day care caseloads would qualify under the Medicaid regulations for nursing home care. Of this percentage 28 percent would be classified as skilled care residents, 25 percent as Intermediate I residents and 47 percent as Intermediate II residents.[2]

The major limitation to a statewide establishment of medically oriented adult day care centers is the possibility of their services being used in addition to, rather than a substitute for, nursing homes. The existence of the adult day care homes would then increase overall costs without reducing institutionalization. This occurrence may be anticipated if the services are made available to all those who need preventive medically oriented adult day care rather than nursing home residents or those about to enter nursing homes. The level of care to be provided by medically oriented adult day care would need to be determined for target population parameters to be developed in accordance with a specified budget threshold.

In a recent needs assessment survey of six HRS districts, transportation resources were designated as a major factor limiting the widespread implementation of adult day care. The transportation limitation was also noted in HRS' "Evaluation of Florida's Community Care for the Elderly Program" with the following recommendation: "Adult day care programs and senior center programs are recommended for more densely populated areas, because of the costs involved in transporting clients to the center. Senior center care is more appropriate for less impaired, more independent clients; day care is appropriate for more impaired but still mobile clients".[3]

The transportation limitation is an important variable in site location planning. With the increasing energy costs, there may be a future need to distinguish between urban and rural service models. The allocation of HRS district service centers has been accomplished by using clients' zip code numbers aggregated as the site parameters. Bid sites are chosen for their close proximity to the largest number of client residences. A similar plan could be used to locate medically-oriented adult day care.

However, such an effort could be too costly, if there were no existing structures to occupy. Start-up costs for new facilities are extemely high. This causes the adult day care center's per diem rate for the first few years to run higher than the average nursing home per diem which covers twenty-four hour care. Therefore, it is advisable to use existing facilities to establish medically oriented adult day care centers. One means could be to confer with Boards of Education on future plans to close existing public schools in neighborhoods with a declining school-age population. An agreement might could be developed between state and county officials to use closed school facilities for medically oriented adult day care.

Another recommendation on the use of existing facilities was made in the 1976 Senate HRS committee report on the elderly. This report encouraged the use of nursing homes to provide necessary medical attention for the elderly and allow them to return in the evenings.

Mr. Art Harris, Florida Health Care Association, proposed in 1978 that existing nursing home facilities could be used to provide potentially 3,000 adult day care slots in Florida at an estimated per diem rate from $7 to $10 Development of adult day care programs in existing nursing home facilities would allow maximum use of nursing homes and provide for quicker development of adult day care programs.

ADULT DAY CARE PROGRAMS IN FLORIDA

The first adult day care program in Florida was established in 1968, with Title III of the Older Americans Act funding, as a part of the Pinellas Neighborly Center. The Neighborly Center was incorporated in 1966 as a Senior Center and, after completion of a needs assessment project in 1967, the adult day care program was added. Since 1968, the Neighborly Center's adult day care program has expanded to five sites with a sixth site to open in April 1980 with additional Community Care for the Elderly state funding.

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[2] DHRS Evaluation of Community Care for the Elderly Program, 1978, p. 68.
[3] Ibid, p. 79

There are currently twenty-one adult day care centers in Florida funded through Title III of the Older Americans Act and Title XX of the Social Security Act. The local match requirement varies from 10 percent to 25 percent. These are primarily "socially oriented" adult day care for the frail elderly with limited incomes.

The 1976 Community Care for the Elderly Act (CCE) authorized the funding of two day care programs in addition to home delivered services, multi-service senior centers and family placement. The evaluation results of the two CCE adult day care demonstration projects influenced the statewide implementation of adult day care in eleven sites beginning January 1980. One of the CCE demonstration projects is a medically oriented day care program and the other is social day care. Both will be further discussed.

Caseload, utilization, recipient characteristics, and per diem costs

A telephone survey of eleven Florida Adult Day Care Programs, coordinating the twenty-one federally funded adult day care centers, was conducted to obtain pertinent information for an initial analysis of adult day care clients and services/costs (See table 1). All but the two Title XX funded centers are being funded by the Older Americans' Act (Title III) and the required local revenue. Many of the adult day care centers were provided county, municipal or church owned space as in-kind match in addition to United Way, county and municipal governments, and other agencies' cash donations to meet the federal/local match requirement.

Table 1

Florida's Titles III and XX Adult Day Care Programs

District	Center	Revenue Federal	State	Local	Donations	Total	# Sites	# total Slots	Average * Daily Attendance	Per Diem
V	Pasco Mental Health Services Adult Day Care	Title III $112,734		$12,565		$125,299	2	60	52	$19.33
	Pinellas Neighborly Center	Title XX $265,654	$29,930	$33,207	$28,000	$356,291	5	175	175 **	$10.00
VI	Hillsborough Senior Day Care	Title III $120,000		$163,713	$825	$284,538	4	100	80	$15.97
	Manatee Adult Day Care	Title III $29,997.25		$5,460.49	$4,538.60 (in-kind)	$39,996.34	1	30	10 to 20	$10.00
VII	Orange County Adult Day Care	Title III $50,276		$10,074	$1,580	$61,930	1	25	22.5	$15.00
X	St. George Senior Day Care	Title III $56,785		$11,037 (cash) $ 6,309 (in-kind) $19,536	$2,194	$78,515	1	35	35 **	$9.75 (not including transportation)
	S. W. Senior Day Care	Title III $58,946		$6,564	$352	$65,862	1	45	45 **	$12.00
	S. E., Senior Day Care	Title III $49,380		$5,414		$54,794	1	35		$12.00
XI	South Beach Adult Day Care	Title XX $60,373	$12,074	$8,050		$80,497	1	50	37	$15.00
	Metro Miami Adult Day Care	Title III $196,293		$39,252	$26,173	$261,718	4	110	100	$17.00
	Total	$1,000,438.25	$41,504	$303,835.49	$63,662.60	$1,409,440.34	21	665	85% daily occupancy rate	$13.60/average

*Does not differentiate between full-day or half-day attendance

**More participants are scheduled than slots available

The per diem costs for these socially oriented adult day care centers range from $9.75/day to $19.33/day. Major cost factors that are not included in some centers' per diem calculations are meals provided through Title VII, transportation provided by the county or city, and special therapeutic services that are donated, e.g. speech and physical therapy. However, some adult day care centers include the aforementioned costs, as well as donated space costs, in their per diem calculations which causes so much variation in the per diem costs. The average per diem cost for the surveyed adult day care sites is $13.60 per day.

The average number of participants at the twenty-one sites is 30 per day. The range is from eighteen to forty-five per sites daily attendance. The occupancy rate range is from 66 percent to 100 percent with an average 85 percent daily attendance rate. The variation may be in part explained by the different enrollment procedures by centers. A number of the centers enroll more clients than slots are available in recognition of the average weekly attendance being 2.5 to 3 days per week. However, some of the centers enroll for just the slots available expecting five days per week attendance. One adult day care center director with such a policy noted there was a "serious problem with no-shows."

Prior to September 1979 the adult day care centers reported costs on a per diem basis in the quarterly reports submitted to the HRS Aging and Adult Services Office. The latter found the per diem unit of analysis unsatisfactory since Florida adult day care centers vary in the number of hours open daily. Some centers are open from 7:30 a.m. to 5:30 p.m. daily to accommodate clients transported by working relatives. Whereas, other centers are open from 9 a.m. to 3 p.m. with center-provided transportation beginning at 8 a.m. and ending between 4 and 5 p.m. The variance in the number of hours open and the fact that some clients only attend for a portion of a program's day, lead to a reporting change from a day to an hour as the unit of cost reporting. The first quarterly reports using the hour as the reporting cost unit were submitted in January, 1980.

Variations in the cost reporting by adult day care centers may still be expected based on the differences in services provided, staff/client ratios and the distance parameters for transportation. One adult day care center will provide transportation to clients within a five mile radius; whereas, other adult day care centers provide transportation to only a few clients because of the lack of vehicles. The Pasco County Mental Health Services Adult Day Care Centers have transportation waiting lists with slots available at their two sites. They could accommodate forty more clients daily at the two locations, but each site had only one van.

The costs for adult day care are also influenced by the kinds of services offered and the staff/client ratios. The adult day care centers which provide a health component through center staff with a medical background, e.g. an LPN or RN, do report slightly higher costs for services. Since the medical component for the Titles III and XX funded Adult Day Care Centers includes health support activities rather than primary medical care, the cost differntial is not very large. The cost impact seems to be greater for centers with a low client/staff ratio in addition to medically oriented staff.

Again, there are extenuating circumstances to be analyzed for the adult day care centers do vary in their use of volunteers to supplement the daily service programs. For example, the Miami Metro Adult Day Care Centers report a 1: 10 ratio for salaried staff to clients. However, the four Metro Centers have an extensive volunteers' program which augments the staff/client ratio to 1: 5. The volunteers include student nurses supervised by a county provided nurse who also does the initial health screening and on-going health counseling. None of these medically related costs are included in the per diem calculations averaging $17 for the four Metro Adult Day Care Center.

A last factor to be considered in the cost analysis is the variation in recipient characteristics. For example, the Miami Metro Adult Day Care Centers serve many post-stroke victims who live alone. This is a particularly vulnerable population group with many social and medical needs. However, another adult day care center in Hillsborough County requires participants to be in "reasonably good health and able to take one's own medication" in order to attend the center. The most common admission criteria across the Florida Adult Day Care Programs includes the frail elderly in need of a protective environment. A large majority of the clients being served are below the poverty level which may be an indicator of an elderly person's need of a protective environment. The Miami South Beach Adult Day Care Center Director foresees the elderly's unmet needs to be reflected in the fact that at least 70 percent of their recipients are SSI eligible, but many do not apply because of the perceived welfare stigma. However, these same elderly will attend the Title XX funded, South Beach Center because individual income data is not requested. In accordance with the Title XX group eligibility regulation, as long as 75 percent of the recipients have incomes at less than 90 percent of the State's median income, individual income determinations do not have to be completed. The Title III funded centers also do not mandate income criteria since the only service regulation is that recipients have to be over sixty years of age.

Nevertheless, the majority of the elderly in Florida's Adult Day Care Centers are on limited incomes. All of the Directors surveyed indicated that income assessment is an informal part of a Center's determination of a prospective recipient's need for service. This initial assessment for service needs also includes a physician's report and usually an interview with an applicant's family when they live together.

The latter is necessary to ascertain the need for a daily protective environment and the capability of family members to transport an elderly relative to the adult day care site.

SUMMARY OF TITLE III AND XX ADULT DAY CARE

In summation, the average Adult Day Care Center caseload is thirty recipients daily with an 85 percent average daily occupancy rate. The telephone survey data results indicate that the occupancy rate could be increased in two ways: (1) by providing more transportation; and (2) by tracking recipients over a specified time period, e.g. a month to derive an average weekly attendance rate. Then more recipients could be admitted than slots are available since most clients do not attend 5 days every week. None of the surveyed programs had a policy on length of stay. It is viewed as a variable dependent on a recipient's health. Most terminations are due to a worsened rather than a better physical and/or mental condition. However, three of the adult day care programs associated with multi-purpose senior centers do encourage movement between the programs based on a clients' health and daily living skills. It should be noted that a stabilization of condition is being considered a success by many professionals in adult day care programs.

The average per diem cost for "socially oriented" adult day care is $13.60 with a range of $9.75 to $19.33. There are numerous intervening variables to be considered in costs comparisons: staff/client ratios, extent of volunteers' use, transportation and meals costs, types of services, and types of clients served according to their physical and mental condition, living situation and income.

The composite picture of an adult day care center recipient may be summarized as follows: A frail, elderly person around seventy-five years of age capable of at least one daily living skill although often in chronically ill health and in need of a protective daily environment usually because of a limited income that isolates so many of the elderly living alone. The percentages vary by site from 34 percent to 75 percent but many adult day care center directors felt that a majority of their recipients would be in nursing homes if it weren't for the adult day care program. The recipients' living situations vary by program. An adult day care center with comprehensive transportation services is more likely to serve the elderly living alone. Whereas, the centers with very little available transportation are more likely to serve the elderly living with relatives or friends able to provide transportation.

Since all of the surveyed adult day care centers serve clients with a variety of impairment levels, it was not possible to correlate the per diem cost variation to specified levels of care required. However, a trend developed out of the telephone survey of higher per diem costs for facilities serving higher age group clients, e.g., average age over seventy-five. Since deteriorating health is often a factor of increasing age, the higher per diem costs for older age groups is reflective of the significant relationship between levels of impairment and costs of care.

Community care for the elderly programing

As aforementioned, the 1976 CCE Act funded two demonstration projects for adult day care. The Margate Day Care Program is basically a social program including social services, supervision, a meal and snacks, recreation and some health maintenance services. There is a registered nurse on the staff and a Broward County Medical Resource Center physician assists in the medical screening and limited medical care.

The Medical Adult Day Care Program is provided through the Miami Jewish Home and Hospital for the Aged (MJHHA). Medical day care includes all the social services listed above as well as needed medical care and is intended for people with more serious chronic health problems. The MJHHA is a comprehensive 315-bed nursing home with a 32-bed specially licensed geriatric hospital. The MJHHA adult day care clients have access to physiotherapy, a complete range of medical specialists, X-ray services, laboratory services, pharmacy services and mental health service.

A 1978 HRS evaluation of these two adult day care programs included an assessment of the change in impairment levels receiving adult day care services over one year. The Multidimensional Functional Assessment Questionnaire (MFA) yielded impairment measures for social resources, economic resources, mental health, physical health, and daily living skills. The MFA sources are as follows:

1 = Excellent health or status.
2 = Good health or status.
3 = Mildly impaired status.
4 = Moderately impaired status.
5 = Severely impaired status.
6 = Completely impaired status.

A score of one or two represents an independent person. A score of three indicates the need for early intervention services to arrest the process of decline. Scores four, five, and six represent a high risk group for nursing care with six representing the bed-ridden or completely psychotic.

CHANGE IN MEAN IMPAIRMENT LEVELS [1]

Dimension	Margate		MJHHA	
	Mean impairment time 1	Change in mean impairment, time 2	Time 1	Time 2
Social	3.6	+1.1	3.7	+.4
Economic	2.6	+.3	2.7	([2])
Mental health	3.1	([2])	3.4	+.5
Physical health	4.5	+.8	3.5	+.3
ADL	4.3	+.1	3.7	+.3
Number interviewed	n = 11		n = 29	

[1] Ibid, p. 50.
[2] No change.

The evaluation findings note that the greatest improvement in mental health occurred among MJHAA day care clients; this was the only client group with access to a full range of mental health services. Evaluation staff also noted that the unusually friendly atmosphere at Margate which they felt assisted the great improvement in social resources. The table results reflect an overall success rate in that there was no decline in the status of the adult day care recipients. The sample groups were small, especially in Margate, so that scores should be used to make only program inferences.

The HRS evaluation of CCE did not include a cost comparison of Margate and the MJHAA Adult Day Care Centers since the latter did not include the medical costs in their cost reports. The evaluation findings do note that the Margate day care program appeared more cost effective than the MJHHA program based on a comparison of their social services and reported costs. Yet such a comparison is difficult since the medical component is intertwined with all the other services provided at the MJHAA for the Aged Adult Day Care Center. In addition, evaluation findings also note that the two day care programs are both less expensive than nursing home care for comparably impaired elderly.

The per diem cost for the MJHHA medical day care program was recently calculated at $24. Whereas, the Margate social day care per diem rate ws $16.25. The maximum per diem for nursing homes ranges between $25 to $31 bassed on the level of skilled care needed. A cost comparison between these service programs would have to take into account the average daily attendance by clients in adult day care. The national average of 2.5 days per week and the telephone survey results of Florida's 2.5 to three days per week attendance would lower the monthly costs for adult day care in comparison to the nursing home cost.

The CCE demonstration projects' program and cost benefits have resulted in a statewide implementation of CCE adult day care in addition to the other care services. Table 2 delineates the site, funding and program information on the eleven centers.

ANCILLARY SERVICES WAIVER PROJECT

HEW recently approved the HRS 1115 research and demonstration project "Ancillary Community Care Services, A Health Care System for Chronically Impaired Elderly Persons." The Department submitted a 1115 Waiver application in 1978 to waive a number of Title XIX rules and regulations in order to obtain Title XIX funding of the Ancillary Community Care Services Project. In addition to other community care services, medically oriented adult day care will be funded, in part, by Title XIX funds for the first time. There will be five adult day care programs funded under the demonstration project. The project will be designed to develop and evaluate a variety of intense medically oriented home delivered, day care, and medical-social assessment services aimed at meeting the needs of persons age sixty and older. Project activities are proposed for Duval, Pinellas, Polk, Broward, and select areas of Dade County. Participants will be selected from the noninstitutionalized, Medicaid eligible, age sixty and older population. The specific waiver requested that adult day care services be provided under the direction of a physician. The day care project services will be directed by an Advance Registered Nurse Practitioner or a registered professional nurse.

OTHER STATES MEDICAID PROGRAMS

A 1975 Comparative Study of Adult Day Care in the U.S. included three Medicaid funded programs in the study sample size of ten different programs. All of the three Medicaid reimbursed facilities were affiliated with a long-term facility from which they received in-kind or direct support. The study found that affiliated adult day care centers were able to offset expensive medical services in their per diem calculations. A major reason for this is the location of the adult day care centers in existing medically oriented facilities. As the study further noted, costs are inevitably higher for new programs not yet at a fully operational level. Additional summarized findings are as follows:

Nursing services is the function with highest per diem costs under health services;

Nursing homes may be cheaper for participants so impaired that they need day care more than about three days a week;

Transportation is the most expensive non-health activity; and

Benefits in adult day care may far outweigh added costs of care. The study suggests the need for outcome studies to pursue this point.

Table 2

Six-Month CCE Statewide Implementation Project
January 1 - June 30, 1980

District	Sponsor or Center	Revenue State	Local	Total	# Slots	Estimated Per Diem	Estimated Medicaid Eligibl
II	Bay County Senior Adult Guidance Program	$34,523.	$3,836.	$38,359.	20	$15.34	86%
	Leon County Senior Society Planning Council	$26,857.74	$2,984.19	$29,841.93	20	$13.94	60%
III	Advent Christian Home	$20,905.29	$2,322.81	$23,228.10	12	$16.13	50%
V	The Neighborly Center	$31,178.70	$3,464.30	$34,643.	35	$10.00	80%
VII	Orange County Advisory Council on Aging	$45,600.95	$5,066.80	$50,667.75	23	$17.48	65%
	Brevard County	$46,908.	$5,212.	$52,120.	30	$16.24	80%
VIII	Sarasota Senior Friendship Soc.	$43,621.20	$4,846.80	$48,468.	30	$15.10	60%
	Lee County Senior Friendship Society	$81,151.20	$9,016.80	$90,168.	40	$20.31	4[illegible]%
	Polk County Board of County Commissioners	$19,969.76	$2,218.86	$22,188.62	15	$13.82	67[illegible]
X	N. W. Senior Center	$60,331.50	$6,703.50	$67,035.	40	$14.00	50%
XI	Miami Jewish Home and Hospital (Medical Orientation)	$24,570	$2,730.	$27,300.	15	$24.00	60%
		$435,617.34	$48,402.06	$484,019.40	250	$16.03/average	

Georgia's alternative health services project

The goal of Georgia's seventeen county demonstration project is to test the effectiveness of comprehensive, Medicaid-funded community-based services as an alternative to nursing home care for the elderly. A 1979 program evaluation compared twelve-month recipients of project services with control groups. The available project services are Adult Day Rehabilitation (Day Care), Alternative Living Services, and Home-Delivered Services. The project's admission criteria include clients who are living in a nursing home or had applied for nursing home care and those who were identified as at risk of entering a nursing home within six months.

The evaluation found that the higher risk recipients of project services had a lower mean monthly cost of all Medicaid services than the control groups not provided project services. On the other hand, recipients of project services who were categorized as at lower risk or nursing home entry cost the Medicaid program less per person than high risk service or control group members.

The mean monthly costs of Adult Day Rehabilitation per person was $222 with a standard deviation of $118 for a sample size of ninety-five clients. Data was provided on average weekly attendance in order to calculate a per diem cost. However, the evaluators favorably compared the average adult day care monthly cost of $222 to the $491 mean monthly cost to Medicaid for Intermediate Care Facilities in Georgia.

The Adult Day Rehabilitation component provides ambulatory health care and supportive services to the chronically ill or convalescing elderly. Most of the clients were recently discharged from a nursing home, hospital or other institution. The following services were provided:

Daily nursing services.—Monitor vital signs, supervise medications, health counseling; coordinate and supervise treatment plans with physicians.

Medical social services.—Support participant and their families; coordinate care plans with the nurse; coordinate community services to meet client needs.

Planned therapeutic services.—Crafts, music, educational and cultural programs.

Physical therapy, speech therapy, and occupational therapy.—One Meal Per Day; supervision of Personal Care: Assistance with dressing, personal hygiene and maintenance of clothing; transportation, if necessary; and special Medical Appliances and Equipment which are not otherwise covered by Medicaid but which are prescribed by a physician to serve a medical purpose, prevent illiness or injury or maintain or improve functional independence.

The 1979 evaluation reported that actual costs for Adult Day Rehabilitation exceeded contracted charges because many of the new programs were unable to increase their client populations quickly enough to offset the start-up costs. However, the reported rates were not adjusted following audits since the programs now have a client base which allows efficient use of staff, space and transportation.

The evaluators compared mortality rates between project and control groups as the primary effectiveness measure. There was a significant (p. 01) difference in mortality within twelve months of enrollment between higher risk project members (18 percent) and higher risk controls (45 percent).

In summary, project services appear to have increased longevity for those clients who were classified as at higher risk of entering a nursing home within six months of enrollment. Analyses of data on the mortality, functional status and morale of project participants indicate that project services increased longevity within twelve months of enrollment. These preliminary results offer evidence that a system of community-based care can support nursing home eligible Medicaid recipients at an average monthly cost per recipient which does not exceed the existing long-term care system. Alternative Health Services, Annual Report, Georgia Department of Medical Assistance.

California's adult day health care program

The California Adult Day Health Care Act, AB1611, was passed in 1978 after a successful implementation of three adult day health care center (ADHC) projects. In 1976, California received a Section 1115 Medicaid Waiver to test the success of the first ADHC project, On Lok, in two other environments. The program objective was to "facilitate the development of a state funded adult day health services program by expanding the testing of adult day health services as a new health care delivery system designed to meet the special needs of the elderly and disabled by maintaining them in the community."[illegible]

Summary of evaluation findings.—Medicaid costs were significantly lower for persons in Adult Day Health Care than for persons in the control group; Average monthly Medicaid costs for ADHC were $226.60, 44.4 percent less than the average Medicaid skilled nursing facility monthly reimbursement, 67.55 percent less than

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[illegible] Ruth Von Behren, "Adult Day Health Services Final Report," 1978, p. 3.

the average Medicaid reimbursement for the San Diego control group, and 4 percent more than the combined control group monthly average ($217.54); and Effectiveness Performance Objectives were met 75 to 100 percent of the time, e.g., one hundred of those clients who had been told by their physicians that their only alternative to nursing care or a mental facility was adult day care, were maintained at home with ADHC services.

Medicaid participants were 72 percent of the ADHC population. The per diem cost of care at the On Lok facility in 1978 was $24. The average days per person per month was 12.34. However, fluctuations in the average daily attendance reduced the monthly costs of care.

The cost effectiveness of the program resulted in the 1978 Legislative appropriation of $100,000 in start-up funds for adult day health care centers. The Adult Day Health Care Act of 1978 established ADHC as a Medicaid Program with the following per diem rates:

Base	$19.86
Adders:	
Meals	.14
M.D	.21
Transportation	2.31
10 percent geographical differential	1.88
Maxmium	24.40

The Legislative Act authorized the provision of adult day health care on a short term basis as a transition from home health to personal independence, or on a long-term basis as an option to institutionalization. The Act's guidelines are as follows:

1. ADHC centers must be a community-based service with heavy community involvement.
2. The centers must be accessible to the low income elderly.
3. Growth of the program should be planned and controlled.

The last point emphasized the concern of some California administrators that rapid uncontrolled growth would occur. As a result, a county plan must be developed by an Adult Day Health Planning Council comprised of senior citizen representatives and representatives from state aging and health programs. The state has approval power of the plan and individual provider applications. All providers must be Medicaid licensed every twelve months after an on-site financial management, medical, and standards review by state health officials. A final control is the 1978 Act's "sunset clause" which means the law will expire after five years unless new Legislation is passed.

MARYLAND'S MEDICAL DAY CARE PROGRAM

Maryland began reimbursement for medical day care in January 1, 1980. The reimbursement is on an interim per diem and cost-related basis and may not exceed 75 percent of the comprehensive long term care rate. The rate ceiling is $24.98 per day for fiscal year 1980.

Eligibility criteria for medical day care include a Medicaid eligibility and PSRO certification for long term care. Specific medical day care services must be physician ordered, and each participant must have a plan of care established by a physician and updated every ninety days.

A medical day care provider must have as a minimum a full-time registered nurse, a part-time activities coordinator, a part-time social worker associate, and a staff physician who may be full-time, part-time or contractual. A full-time staff member must be designated as the Health Director. The minimal acceptable staff ratio is one staff member to six participants.

The following services are mandatory: (1) Medical Services; (2) Nursing Services; (3) Physical Therapy and Occupational Therapy as needed; (4) Personal care; (5) Nutritional Services; (6) Medical Social Services; (7) Activity Program; and (8) Transportation as needed.

The above services must be ordered by the participant's physician as part of the plan of care, medically necessary, and provided to participants certified as requiring at least intermediate nursing facility care.

NEW JERSEY'S ADULT DAY HEALTH CARE

A facility must be licensed as a long-term care facility by the Department of Health to participate in the New Jersey's Adult Day Health Care Program. Approval by the State Medicaid Program is also required. New Jersey is planning to expand the program to reimburse providers other than nursing homes for medical day care.

New Jersey reimburses each long-term care facility 75 percent of their ICF-B rate. The average cost per day is $23.12. This rate does not include physical and speech therapy services which are billed separately. The program has been in operation for two years and presently reimburses for medical day care to three hundred Medicaid recipients. All billing is done on a monthly basis and cannot be submitted later than ninety days after the date of service.

WASHINGTON'S ADULT DAY HEALTH CARE SERVICES

Adult day health care services in Washington are Medicaid reimbursed to facilities with a contract for day health services with the Area Agency on Aging. The Area Agency must be willing to use some of its State funds as match for the federal portion of the Title XIX reimbursement for those recipients over sixty years of age. If the Title XIX client is under sixty years of age, the entire per diem will be reimbursed. The maximum Medicaid reimbursement for day health care is $20 per diem, which includes $2.00 per client per day for transportation.

The adult day health programs must operate at least five hours a day, three days a week and provide at least one meal per day. A physician's written approval for day health services is required.

NEED INDICATORS FOR MEDICAL ADULT DAY CARE IN FLORIDA

Florida's population over sixty years of age is projected to increase by 75 percent between 1977 and 2000. The elderly population is currently estimated at 2,295,678, approximately 23.2 percent of Florida's population. Dade County has more individuals over 60 than sixteen other states. Pinellas and Hillsborough Counties have more elderly than twenty-one other states.[5]

Approximately 1[illegible]0,000 noninstitutionalized elderly have been identified by the HRS Aging and Adult Services Office as having an unmet need for some type of long term care. There are an estimated 300,000 elderly in Florida below the poverty level. The percentage of elderly below poverty ranges from 40.4 percent in Dixie County to 9 percent in Broward County.

A 1979 legislative report on Aging quoted national data indicating that as many as 320,058 functionally impaired elderly Floridians may be in need of long-term care services. In addition, there are approximately 27,000 elderly in Florida nursing homes and 1700 geriatric patients in state mental hospitals. There were 13,688 elderly patients in Florida's nursing homes in June 1979 that received Medicaid reimbursed services.[6]

An immediate need indicator for adult day care is the waiting list number for the existing adult day care centers in Florida. Ninety percent of the surveyed centers had waiting lists of over ten applicants. As one surveyed director noted, the waiting list number would be much higher if the program was publicized. Also, a majority of the state's communities do not even have an adult day care center, much less a maintained waiting list for care.

As discussed earlier, the HRS Office of Evaluation and the Florida Research Center, Inc. have conducted evaluations of adult day care programs funded under the Community Care for the Elderly Act. The results of the evaluations of community care programs, including adult day care, support the concept of adult day care: on the average, clients became less impaired; the programs met the client perceived need for services; the rate of entry into nursing homes for clients in the program was less than half that for the general population; and the cost of services was less expensive than the least expensive level of nursing care.[7]

Recommended program improvements

In 1977, the House Committee on Health and Rehabilitative Services included the following recommendations on Florida's Medicaid Program:

The funding and administration of Florida's Medicaid Program should be oriented so as to concentrate as much on keeping its citizens well as on curing their sickness.

The focus of Florida's Medicaid Program should be altered so as to place greater emphasis on health care provided through alternatives to institutionalization.

Furthermore, the Legislative Committee recommend in their 1979 report on Aging that health-related treatment be advanced in some of the licensed adult day care centers. The Ancillary Services Waiver Project will fund five demonstration medical adult day care centers. However, the unmet need for this service is statewide. The Medicaid program is currently modeled to assist elderly persons whose health is in a critical state, often requiring institutionalization. Community provided services are essential to address the chronic needs of Florida's aging population before the requirement for skilled care is necessary. Department of Health, Education and Welfare statistics indicate that more than 40 percent of all non-institutionalized persons over sixty-five years of age and older were found to be limited in their activity by chronic conditions. In addition, the severity of these disabilities increase dramatically with age.

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[5] University of Florida, Bureau of Economic and Business Research, Older People in Florida: A Statistical Abstract, 1976, p. 85.

[6] Report of the AD Hoc Subcommittee on Aging, "Aging: A Realistic Commitment," 1979, p. 170.

[7] HRS Evaluation of Community Care for the Elderly Program, p. 60.

The current Medicaid average remibursement rates to nursing homes are as follows:

	Averages per month	Maximum monthly rate
Skilled care	$652.41	$911
Intermediate I	569.47	839
Intermediate II	469.18	720

A cost/benefit comparison of the nursing home reimbursement rates to medical adult day care would have to consider the latter's days' attendance per month and hours per day for Medicaid reimbursement. The $24 per diem rate calculated by the Miami Jewish Home and Hospital Medical Adult Day Care Center is comparable to national statistics and will be used for comparative purposes for a six- to eight-hour service day.

MEDICAL ADULT DAY CARE: $24 PER DIEM

12 days per month	$288	3 days/week
16 days	384	4 days/week
20 days	480	5 days/week

The cost comparison is favorable to medical adult day care with the assumption of comparably impaired individuals at the intermediate level being eligible for either nursing home care or medical adult day care. The medical adult day care rate does exceed the Intermediate II rate by $35/month when a person attends every program day for a month. As national data and survey results indicate, the average weekly attendance is 2.5 to 3 days per week. This correlates to a $156.88 monthly cost reduction for a person attending a medical adult day care center three days a week, but eligible for Intermediate II care.

Title XIX funding of medical adult day care

Applicable Title XIX regulations or guidelines that apply to the funding of a day hospital or day treatment services program are as a follows:

Utilization review

The medical review requirement applicable to inpatient hospital and nursing home services must be used for adult day care programs. These regulations require a medical review, including medical evaluation, of the need for care in an institution and provide a prescribed plan of care. This review must be made prior to admission to an institution to determine a plan of care.

Federal financial participation (FFP)

FFP is available under Title XIX for day hospital or day treatment services under the outpatient hospital or clinic services definitions in the Title XIX rules and regulations. Georgia is currently exploring the possibility of funding their statewide implementation of Adult Day Rehabilitation services under the Home Health regulations governing licensed rehabilitative services facilities (440.70E). The direction of HCFA seems to be to develop a new service entitled "Day Medical Treatment" for proposed rulemaking within the next twelve months.

Methods of reimbursement

Reimbursement must be based on the following conditions:

1. Reimbursement authority exists in Section 1905(a)(2) and 1905(a)(9) of the Act, and 45 CFR 249.10(b)(2) and (b)(9), i.e., "outpatient hospital services" which is a requirement for all participating states, and "clinic services."

2. State payment structures will meet requirements for Federal financial participation if the provisions of 45 CFR 250.30(b)(3)(i) and (b)(3)(ii), relating to noninstitutional services, outpatient, and clinical services, are observed. The upper limits for payment will be reasonable and customary charges.

3. As in the Skilled Nursing Facility, where payment is made on a per diem basis according to "customary and prevailing charges," and a few patients receive large amounts of required nursing services while others need only minimal medical attention, this alternative proposal allows the same "averaging out" system for computing reasonable charges in non-resident situations.

4. In the case of a free-standing Day Treatment Center, the upper limits for reimbursement must not exceed amounts paid under Title XIX for similar services in inpatient hospital facilities and skilled nursing facilities, less an amount identified as the part of the cost appportioned to items, services, and equipment required for operation of a twenty-four hour day, such as additional professional third shifts in a twenty-four hour day occupancy situation, additional housekeeping personnnel and skilled workmen, light and heat, etc. In determining indirect costs, expenditures for sophisticated equipment, ordinarily required only in the fully-equipped inpatient facility, should be disallowed.

In determining reasonable cost, in negotiations with a facility which is Title XVIII certified (or like facilities), the regulations of 20 CFR Chapter III may be used as a basis for identifying amounts to be deducted for the Day Hospital Program.

In both the Day Treatment Center and the Day Hospital Program, that part of the cost which represents a substantial savings (i.e., the deductible amount for items apportioned to non-residency) should be carefully negotiated by the state. In this way, the cost of a "package" of services will be reduced by the efficient use of expensive capital without incurring costs of twenty-four hour operation facilities. Negotiations should be undertaken facility-by-facility or on the basis of average charges in the locality. Care should be exercised that there are no unnecessary additions, in terms of personnel and equipment, which could nullify some or all of the cost savings where feasible and in the best interests of the patients, of ambulatory services.[8]

Program standards

Federal guidelines outline the following program standards:

1. To describe in writing its philosophy, objectives and program for providing medical and ancillary health-related services to non-resident registrants in its facilities.

2. To provide a comprehensive assessment of the health status and the related social, psychological, and cognitive needs of each individual patient and to make a determination of the range and kinds of services required. These determinations must be made prior to the registration of the patient in order to demonstrate satisfactorily the suitability of the program for the patient's needs.

3. To demonstrate to the satisfaction of the State agency that the organization has adequate staff and facilities to provide the planned services for the types of patients described in its program scheme.

4. To insure that the assessment of need and the individual treatment plan are professionally prescribed by a physician or other suitably recognized practitioner or interdisciplinary team; and that qualified supervisory personnel, approved by State Licensure, carry out the plan of care.

FUNDING ALTERNATIVES

CCE funds

The proviso language for the Community Care (Core) Services authorizes a ten percent local match requirement for the ninety percent General Revenue funds (See Table 2, Page 15). The General Revenue appropriated for Community Care for the Elderly must be used to fund at least three of the eight core services.

The CCE target group is as follows: Age 60 and older, functionally impaired from: Nursing homes, State facilities, and community residents in jeopardy of a nursing home or other institutional placement.

Approximately 60 percent of the population targeted for CCE funded adult day care has been identified Medicaid eligible without any income criteria mandated under the existing program. The Medicaid eligible population varies by an adult day care center's location and outreach activities to make the service known to frail elderly with poverty level income. At this point in time, there has been little need for outreach activities because of the limited funding for adult day care programs and the waiting lists for service. Therefore, the 60 percent Medicaid eligible elderly targeted for adult day care may be representative of a low estimation for service need.

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[8] Information Memorandum, SRS-M776-3 (MSA), January 22, 1976.

The 1979-80 CCE appropriation is $3.4 million of that sum, $1,053,617 is allocated for adult day care programs. Of the annual allocation of approximately $1 million, $343,000 has been earmarked for the adult day care services that will be provided through the Ancillary Services Project (the Title XIX waiver project).

The remaining $710,617 could also be used to earn Title XIX funds, CCE funding for adult day care programs consist of 90% state General Revenue funds and 10 percent local matching funds. Based on estimates of the CCE adult day care program proposals and the results of a telephone survey conducted by the Medicaid office approximately 60 percent of the current adult day care caseload is Medicaid eligible. A proportionate share of the state funds could be used to earn Title XIX funds for medically oriented adult day care.

The following analysis contrasts the current CCE adult day care funding methodology and the alternative state—Title XIX funding methodology.

ALTERNATIVE FUNDING STRATEGIES

	CCE general revenue	Required local match	Federal funds	Total
A. Current funding strategy	$710,617	$71,062	$0	$781,679
B. Potential funding strategy:				
Non-medicaid CCE[1]	287,247	28,425	0	315,672
Title XIX adult day care	426,370	0	612,037	1,038,407
Total	710,617	28,425	612,037	1,354,079

[1] 40 percent of the adult day care service population is not eligible for Medicaid. Consequently, approximately 40 percent of the CCE funds could not earn Title XIX funds.

The above analysis indicates that Strategy B would generate $612,037 in federal funding and provide for a total adult day care program of $1,354,079, or $572,400 more than Stragety A. This would increase total adult day care funds by 72.8 percent. Strategy B would also save local governments' expenditures of $42,637. On the other hand, if local matching were still required, local funds could generate $61,204 in Title XIX funds and further expand the total adult day care funds.

The additional funds generated by Title XIX federal financial participation in the adult day care program could allow the use of state and local funds that currently earn Title XIX funds. During fiscal year 1979-80, $110,761 of local and state funds are being used to earn $326,027 in Title XX funds for adult day care. Although the $110,761 would only earn Title XIX funds in the amount of $158,993, $167,034 less than under Title XX, Strategy B earns $569,400 more in federal funds. If this alternative strategy were used, adult care program funding would be released for the funding of other programs or additional adult day care for non-Medicaid eligibles.

It is recommended that a new service be developed for coverage under the State Medicaid Plan for 1980-81. Since HCFA is planning to propose rulemaking for a new service entitled "Day Medical Treatment", it is recommended that Florida use this service title although the term "Clinic Services" will be used in the interim in order to secure Title XIX FFP under the existing regulations.

The intent of the new service, "Day Medical Treatment Clinic Services," is to provide an alternative to institutionalization for the "at risk" population. All services would have to be physician authorized with a treatment plan developed. Since there could be no age limitation under Title XIX and the program justification is to encourage nursing home deinstitutionalization, definite service parameters will have to be developed prior to the program's implementation planned for January, 1981. Budget authority will be requested to adjust the 1980-81 appropriations in order to use part of the CCE funds as match to generate Title XIX funding. A budget issue will be presented in 1981, dependent on cost/benefit data collected that will request additional general revenue funding in order to expand adult day care programs in Florida through the Medicaid Program.

The Florida Medicaid Office has requested technical assistance from HCFA's Region IV and Central Offices. Their representatives will be providing this assistance within the next few months so as to plan for the receipt of Title XIX FFP for medically oriented adult day care under the existing regulations for a specified target group, i.e., Medicaid recipients "at risk of" institutionalization or in institutions.

Finally, it is recommended that additional study be conducted on the viability of implementing a separate component of Day Medical Treatment Services to provide for short-term day treatment for persons who would otherwise be inpatients in hospitals. The American Cancer Society has recommended that such facilities be developed for individuals in need of continuous, yet intermittent, chemotherapy as well as other treatment needs that otherwise require hospitalization.

STATE OF MARYLAND,
MEDICAL ASSISTANCE POLICY ADMINISTRATION,
DEPARTMENT OF HEALTH AND MENTAL HYGIENE,
Baltimore, Md., May 6, 1980.

Hon. CLAUDE PEPPER,
Chairman, Select Committee on Aging,
House of Representatives, Washington, D.C.

DEAR CONGRESSMAN PEPPER: I was pleased to have had the opportunity to attend the hearing on day care held by the Subcommittee on Health and Long-Term Care on April 23, 1980. I would like to commend your staff for an excellent job of selecting witnesses who represented various types of involvement with day care and a divergence of opinion as to the value of day care. I was also gratified that the committee stated that written questions would be submitted to the witnesses so they could prepare properly detailed responses. Since this has resulted in the hearing remaining open, I wish to take this opportunity to present my strong support for day care, my response to certain witnesses and some additional information.

Day care definitions

I believe that the testimony indicated that various witnesses and committee members meant different things when they spoke of day care. It is important to carefully define day care in its various guises and modes. Perhaps it is most common to assume that there is only two models of day care, i.e., health oriented or "day hospital" (known as Model I) and socially-oriented or "multipurpose" day care (known as Model II). Because there exists such a tremendous range of services within the health oriented model, I believe these definitions are inadequate. Instead there are really three levels:

Level 1—Day Treatment which is a very intensive rehabilitatively oriented service. It occurs at a day care center affiliated with a hospital or a heavily skilled nursing facility.

Level 2—Day Health or medical day care which is a less intensive rehabilitatively oriented service but provides such services as physical therapy, occupational therapy and speech therapy for those who need it and provides nursing services, social work nutrition, transportation and activities for all participants. It occurs at a nursing facility or a free standing center.

Level 3—Social Day Care which has no therapy or nursing but provides social work, nutrition, transportation and directed activities. This differs from a multipurpose senior center in that there is more staff plus the programs and activities are developed specifically for individuals not just free choice group activities. This type occurs at a free standing facility.

Per diem cost generally declines from Level 1 to Level 3; this is primarily due to staffing requirements but also to the need for specialized activities and equipment for Level 1.

It is not surprising that to a large degree current programs have oriented themselves to satisfy the requirements of funding sources and are not neatly distributed within the three levels. Most day care in the United States is Day Health. I believe that the fact that Dr. Weissert has studied Day Treatment instead of Day Health explains a large part of the discrepancies between his findings and the experiences of both day care providers and state personnel who manage day care programs through auspices such as Medicaid.

Weissert study

Dr. William Weissert in his most recent study entitled "Effects and Costs Of Day Care and Homemaker Services for the Chronically Ill: A Randomized Experiment" has determined that day care is costly and ineffective. When questioned about this study or its implications, he carefully retreats into the complex statistical methodology and states that in this case those were the findings.

I suspect that Dr. Weissert retreats into the study because he realizes that the study has two fatal flaws and several other serious ones. In Dr. Weissert's defense, I am sure that these flaws are much easier to see now than in 1974 or earlier when the study was designed. This is especially true of the first major flaw, which was to study day treatment centers which were intensively rehabilitively oriented and costly. In part they were costly because they were intensive, in part they were costly because they were located in hospitals with high overhead and day care had to assume a part of that overhead. At the time the study was designed, there was a limited number of facilities that could have been studied and a significant portion were of the day treatment variety. Now there are over 600 day care centers and most are of the day health variety. The selection of the centers biased the study tremendously.

Just as the selection of the facilities was critical so was the selection of the population to be studied. At the time, I am sure, there were valid reasons for chosing to study a Medicare population who weren't at risk of institutionalization, but now it seems ill-advised. That the studied population was not at risk of institutionalization is clearly shown by Dr. Weissert's own figures: only 11 percent of the experimental group and 21 percent of the control group used a nursing home. The studied group was not nursing home bound. As was clearly demonstrated by the questions raised at the hearing any federal interest in funding day care is as an alternative to institutionalization, not as an add-on service. Since the Weissert study does not address this need, it is virtually useless.

It would have also been better if a Medicaid population was covered. Since Medicare does not cover day care, the findings are practically moot. However, Medicaid does cover day care as an optional service and is reimbursing for it in seven states. Lessons about day care and the medicaid population would have been valuable. Dr. Weissert himself hinted that the wrong population was chosen when, in response to a question from Rep. William Ratchford as to whether standards were needed, he suggested that the population be narrowed. I believe he felt the population should be narrowed because he knew his population was not at risk.

In addition to the two critical flaws above, both of which I feel invalidate the study there are two other serious flaws. I mention these in the hope that any subsequent study could avoid them. The first is that the providers chosen were not all experienced. This is demonstrated by the fact hat they had trouble filling their quotas and the fact there was no waiting list. Neither case is typical. Ordinarily the only centers that don't have waiting lists or are not filled to capacity are those that are all private pay. However there is rarely a situation where a center with public funding can't fill the funded slots. The very fact that the quotas were unfilled resulted in a higher cost per person per day. In effect the start-up costs were amortized to the study participants.

A second serious flaw is that Dr. Weissert designed the study to determine if day care was an alternative to a skilled nursing facility. Experience has shown that it is more typical for a day care participant to use day care instead of an intermediate care facility not a skilled facility. Again the choice of day treatment model not day health led to the selection of skilled facilities. Yet Medicaid spends billions each year for intermediate care facilities, in some caes for people who don't need to be there.

It is easy to see how this design led to inaccurate results. The first conclusion was that day care is not an alternative to nursing homes. However, if a population that was at risk had been studied, the results would have been quite different. Also day care would have proved to have been more of an alternative if intermediate care facilities, not just skilled facilities, were considered. In Massachusetts where all participants are deemed at risk the staff has determined that one-half would be institutionalized without day care.

The second conclusion was that day care was costly. Part of the cost was due to day care, in the study, not being an alternative service. The costs in the study, which represents 1975 and 1976, were over $50 a day. Yet states that offer day health not day treatment are now, four years later, paying only about half of that. Testimony revealed that Massachusetts is paying $24 a day and Washington is paying $26. California and New Jersey also have rates that are in the low to mid twenties. Interestingly, none of these states are low cost states. If the effect of inflation during the last four years is considered, the difference is even more remarkable.

As day care is typically utilized an average of two or three times a week versus seven days for nursing home care the cost savings grows. Mr. Jeffrey Merrill is correct that no service is more or less expensive for everyone but that it depends on the individual participant. Dr. Weissert has amply demonstrated that for the wrong people, day care costs more.

Georgia alternative health services

The State of Georgia has obtained a waiver to study day care and home delivered services. Their preliminary results are that: "The mean cost per person to the Medicaid program for all services for recipients of project services was considerably lower than the mean for control group member who received nursing home services".[1]

The project services also resulted in significantly lower client mortality rates within 12 months of enrollment with no evidence that the increase in longevity was offset by lower functional status. In effect Georgia is finding that day care and other alternatives when carefully selected are less costly and are an effective service.

General Accounting Office study

The General Accounting Office in its Report to the Congress entitled "Home Health, The Need for a National Policy to Better Provide for the Elderly" published in December 1977 concluded the families will help with the care of the elderly if they are given a respite and some support. Day Care can be a very effective way of providing respite for the family and needed services for the participant.

Cost effectiveness

Many of the questions raised by committtee members indicated concern with whether day care is cost effective. I would like to caution the committee that cost effectiveness cannot be the only standard by which day care is judged. As Ms. Ansak, Executive Director, On Lok Senior Health Services, dramatically testified the cheapest course is to let the elderly die.

When Medicaid was created as the Nineteenth Title to the Social Security Act nursing homes were included as a covered service because it was felt they would be more cost effective than high priced hospital beds. Since then the federal government and the states have spent billions on nursing home care, the costs of the care has dramatically increased, much of the care is inadequate, and now another solution is sought. This attempt to offer alternatives should not repeat past mistakes and just be based on cost effectiveness. Certainly cost is and should be a criteria, but it is no more important than that the care be medically effective, that the quality of life be considered, and that the elderly be treated with the dignity and respect to which they are entitled.

Medicaid and day care

As there are no federal standards or regulations for day care as a covered medical service under Medicaid, an excellent opportunity exists. Day Care can be structured under Medicaid to address some of the committee's concerns. It can be assured that day care will serve as an alternative by limiting it to those who are nursing home bound. In Maryland we limit day care to those who have been PSRO certified as requireing nursing home care.

The cost of day care can also be controlled to some extent as a ceiling could be imposed or the reimbursement rate could be tied to, for instance, a percentage of the nursing home rate for day health and percentage of the hospital rate for day treatment. It should be kept in mind, however, that the average utilization of day care, two or three days a week as opposed to institutionalization seven days a week, is in itself a savings.

Continuum of care

In conclusion I would like to say that Day Care is not a panacea. It can be a very good and useful service for the right person. I believe that this is the key: that the service be appropriate for the individual. Day Care can fill part of this need, but what is really needed is a continuum of services. I strongly believe that the appropriate use of a continuum of services is the cheapest and most efficient use of resources. In many places now, the only choice is nursing homes, which has created an artificial demand. By developing and funding alternatives, the tremendous expenditures for nursing homes will decline and the elderly will have real choices to meet their needs. Hopefully these choices will enable many of the elderly to remain in their homes and communities and to live and die in dignity.

Finally, I would like to send you a report prepared by the Maryland Department of Health and Mental Hygiene entitled "Report and Recommendations on Alternatives to Long-Term Institutional Care". I hope it proves useful. Also I would recommend that the committee give serious consideration to requesting the General Accounting Office to study day care. I have much respect for their work. Unlike some studies which use sophisticated methodology in lieu of common sense, the

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[1] Georgia Department of Medical Assistance, Alternative Health Service Annual Report 1978-79 Atlanta, Ga. p. 120.

GAO has always impressed me as starting with a common sense approach and then doing whatever analysis is necessary to reach a valid conclusion.

If I may furnish the committee with any additional information, please contact me.

Sincerely,

LYDA B. SANFORD,
Chief, Division of Program Development.

Enclosure.

(NOTE.—The report "Report and Recommendations on Alternatives to Long-Term Institutional Care," has been retained in Committee files due to its size.)

SENIOR CITIZENS, INC., DAY CARE FOR THE ELDERLY,
JOSEPH B. KNOWLES CENTER,
Nashville, Tenn.

A day care program for the elderly began operating in April, 1972. It is now under Third Party Funding Provisions of Title XX of the Social Security Act, Social Rehabilitation Services. It is administered by the Tennessee State Department of Human Services. As a United Way Agency, Senior Citizens, Inc. participates in this program.

We now give day care to twenty-one per day who are over sixty years of age and who are at or near the SSI level and who suffer some degree of physical and/or mental handicap due to a variety of causes. Among this target group, it is our aim to reach such individuals for whom our program acts as a deterrent to institutionalization or enables family members to be gainfully employed so as to keep the older person in the home. It is likewise aimed to include those isolated individuals who could profit from culturally enriching experiences and peer-group associations. The program includes transportation, afternoon snack, noon meal, health maintenance services, informational and/or referral services, social welfare services, and a varied program of crafts, parties, and special activities, including trips.

In order to have a capacity load of twenty-one per day, we have worked with about eighty different individuals. The caseload has now narrowed down to about thirty-five. The average attendance is three times weekly. Profile of the program is 85 percent female and 90 percent black. There are also 8 partially sighted participants in the program. These 8 individuals initially presented problems to the staff who had no special training to work with partially sighted individuals; therefore, a program specialist trained in working with the handicapped, has been added.

After a participant has been in the program a few months, we are able to observe remarkable improvement.

Some of the areas where improvement is greatest is in their orientation to time and place; in their improved self-image and positive ego development; in increased physical activity; in conversational skills, in better grooming and cleanliness; and in their overall outlook on life, which is much happier and more optimistic.

Generalized services

1. Counseling with aged individuals and their families.
2. Health supervision of Day Care participants.
3. Motivation counseling aimed at creating and supporting a desire to interact with others, and to become more independent.
4. Group activities in keeping with the needs and capacities of the participants.

Specific services

1. Day care program

(*a*) Includes daily individualized and group activities. Some of these are handiwork, games, crafts, music, art, and various ongoing classes at Knowles Center such as pottery, sewing, communication skills, and emphysema exercises.

(*b*) Includes transportation to and from Center, morning and afternoon group or individual activities, snack time, noon meal, and rest time.

(*c*) Includes definite programs for cultural enrichment: book reviews, travelogues, group singing, and trips to community attractions.

2. Social services

(*a*) Includes evaluation and diagnosis of each participant, with activities planned on individual basis.

(*b*) Includes supportive therapy, crisis intervention, outreach, referral and resource information for participants and their family.

(*c*) Includes motivation counseling by interpretation of behavior and aspects of aging to participants and family members.

(*d*) Includes counseling on all aspects of consumer problems, emphasizing the basic requirements of food, clothing and shelter.

3. Health services

(*a*) Includes individual assessment, determination of medical regime as ordered by physician, advice for those not under medical care so that they can utilize existing health services, selected screening tests, nutrition information, and foot care.

(*b*) Includes emphasis on personal hygiene regarding cleanliness and grooming, with the aim of motivating individual to assume responsibility for self care.

(*c*) Includes daily program of exercises as appropriate for elderly participants.

4. Food

(*a*) Nutrition is included as it is one of the National priorities for the elderly. A definite program is presented giving the participants basic information on food selection and how food relates to their total well-being.

(*b*) Provides a well-balanced three course meal five days a week. Special diets are also served.

(*c*) Provides mid-afternoon snack including either fruit juice or fresh fruit, ice cream, or diabetic fruit, if necessary.

5. Transportation

(*a*) Includes picking up participants and returning them to their homes. A 15-passenger bus owned by the project is used; also we rent an additional van from Senior Citizens, Inc.

(*b*) Includes limited transportation for clinic and doctor appointments where no other transportation is available.

Eligibility for participants

The project is limited to individuals sixty years of age or older who are determined to be eligible under Third Party Funding of Title XX of the Social Security Act. The project is administered by the Tennessee State Department of Human Services.

Senior Citizens, Inc., is a multi-purpose center for individuals fifty-five years of age and older. There are thirteen branches and one mini-center (open five days a week) in the Donelson area. All the branches, including the mini-center are in Metropolitan Nashville. The main Center is open six days a week but the branches meet only on their one day a week. There are 4,200 members of the Center with an average daily attendance of 360 at the main Center and branches. Programs offered by Senior Citizens, Inc., include educational and craft classes, recreational activities, counseling services, health consultation and information, food and rehabilitative services.

There are several other services housed in the Senior Citizens, Inc., building. They are: Foster Grandparents program; Mobile meals for indigent elderly who are referred by Visiting Nurse Service; Homebound meals for those who are unable to prepare their own food, a year-round Trip program, and a second Adult Day Care program which operates five days a week for those who need the service. There is a staff person provided. This program is funded under State funds provided by the Tennessee Commission on Aging.

The Title XX Day Care program, as described, is the other special program at Senior Citizens, Inc. One of the attractions of the Day Care program is that it functions as an integral part of this multi-service agency, giving the participants many more opportunities because of its location. Day Care participants are enrolled in pottery class, emphysema exercises, liquid embroidery, organ and piano, crafts, and also take part in physical fitness activities, as well as enjoying the parties and films.

After 8 years, we are convinced that this type of intervention and the services provided through this program does prevent unnecessary hospital stays or referrals to Nursing Homes. Of the approximately 350 individuals given service by the program, the families have expressed repeatedly how helpful it is. Not all of the 350 were admitted to the program. From the approximately 180 who were participants, we have lost 15 by death, 8 are now in Nursing Homes, and 4 are now in institutions. Some improved to the point that the program was no longer necessary and the others have moved away.

The Day Care program has indeed made life enjoyable again for those who had given up and were just existing. For this we are grateful.

PRIME TIME DAY CENTER,
Evanston, Ill. April 29, 1980.

CLAUDE PEPPER,
Chairman, Select Committee on Aging,
House of Representatives, Washington, D.C.

DEAR CONGRESSMAN PEPPER: I wish to submit the following facts and information to be placed in the Congressional Record as testimony for establishing Adult Day Care Centers for the Elderly.

The recorded interviews with adult-children tell more elequently than descriptions or factual information how effective and accomplishing attendance at Adult Day Centers can be.

The chart defines various types of day care centers and demonstrates the flexibility and adaptibility of the Centers to fit the endless medical, social and psychological needs of the senior citizen.

You are to be highly commended for your efforts in establishing this viable alternative for the maturing adult who otherwise might be condemned to a bleak existence in a nursing home that doesn't answer his/her needs.

Thank you for the opportunity to record my testimony in the Congressional Records.

Sincerely,

SHIRLEY SIDRAN, *Director.*

Enclosure.

Following are interviews with families whose elderly parents are attending the Center

Bob Clark, single and in his early 40's, has had sole responsibility for his mother, Elsie, an 82 year old former piano teacher when she left a long established household in Pittsburgh three years ago. They live in a large apartment building where close to 75 percent of the units are rented by widows 60 years of age and older.

Although it would seem that this environment could provide a large number of potential friends for Mrs. Clark, many of the women have lived in the area for years and have already established personal relationships which she, a transplant from Pittsburgh, has not.

"Mother isn't accustomed to going our and making friends," Clark says. "She doesn't play bridge, and, as her slowing down became more noticeable, it began to make people her age uncomfortable."

Clark read about Prime Time, The Home's Day Center, in the local Evanston Newspaper and says, "It was exactly what I felt was needed." At first he was hesitant to send Mrs. Clark every day, but he found that it was necessary for her to establish daily relationships with people.

"She is now much keener mentally," he says, and credits it to her "having to use her brain every day." She has a better memory, and now her blood pressure has gone way down as well. From the first couple of weeks, I noticed that when I picked her up each day, she was sharper. Now I'm finding I can relate to her as an adult. . . . I have more confidence that when I ask her not to do something she won't do it. She tends to be much less confused. She needed the social interaction very much.

Clark has observed that his mother's endurance is better as well, and that she has become "peppier . . . and more willing to do things."

One Saturday she went with me to pick up a friend at the train, then to her hair dresser, after which we had lunch, went to look at condominiums and do some errands, and finally back to the train—all with only an hour's nap in the afternoon.

Before Mrs. Clark started at Prime Time, her son had to slow his own pace when he was with her for fear of tiring her. But now, for instance, ". . . we have tickets for the piano recitals at Orchestra Hall. We used to leave at intermission, but now we stay for the whole performance, eat dinner, and then come home. Oh yes, she's coming out. She has a friend here too, Ellen. One week Ellen was away and mother missed her. I heard about Ellen every night.

He continues, "This has been a life-saver for her and selfishly, for me . . . if it weren't for Prime Time, I would say that for her own good, we would have to get full-time help during the day or go to a retirement home or a nursing home. And while I feel there is a need for those, I feel that the senior citizen, as long as possible should be maintained at home in a family environment, even a limited one."

Helen Schmidt, age 88, lives with her widowed daughter on the first floor of a two-flat, family-owned building. The second daughter is married and lives with her family on the second floor.

In contrast to Bob Clark and his mother who live alone in a large apartment building, one would think that this integrated family living arrangement would ease Helen's problem of being alone. And for a while it did help, but both daughters, Bea Arndt and Joyce Daley work and Helen was left alone all day.

She had little desire to eat the meals the girls had left for her, lost all motivation to keep herself occupied and became nervous. Medication only seemed to make matters worse. She was not aware of family activity around her, taking no part in family gathers, and seemed to be "totally out of it."

She was hospitalized during the winter to determine the extent of the deterioration and was diagnosed as being over-medicated. Upon discharge, it was recommended that she should not be alone. When asked if Helen could read during the day, her daughter replied, "Yes, she has cataracts, but she can read with the use of magnifying glasses. But I think you can do just so much, you can watch just so much TV. The weather was extremely bad last year. It was hard for us to take her out because of the snow and ice; she was unsteady, so she just felt completely isolated and cooped up. As a result, she became so frustrated that she couldn't deal with being alone each day."

The daughter continued, "We talked to the doctor about a day center, and he thought it was an excellent idea, so we began to look into this type of care—and it has been marvelous for her and for us."

Bea found out about Prime Time by contacting the Commission on Aging in Skokie Village which gave her the name of Prime Time. The two sisters visited the Center where arrangements were made to send the regular Center invitation to Helen, asking her to visit for the day. Helen reluctantly agreed, "but she was going to go just this once, and that was it."

Bea continued, "She came the day of the invitation, had lunch and enjoyed it. That was on Thursday. She went back the following Tuesday and had such a good time that she's been there every day since. . . ."

Joyce commented on the change they've noticed since she attends the Center. "We were remarking this evening that she is so much more alert than she was last winter. Things that she just never thought about any more, all of a sudden are coming back to her mind and she seems to be really 'with it' again. She's still forgetful, but she's not like she was before where you had a difficult time sometimes having any kind of conversation that made sense."

When asked how her attendance at the Day Center has affected their interaction with her, Bea continued, "We certainly feel more at ease. We leave in the morning with the nice feeling of knowing that she's going to be with someone and be happy. When we come home, she's had a good day. It seems now that she's settling down and feels contented. I think she considers it a job. While working with the crafts, she knows she'll be able to sell them when she's finished, and she feels useful. Just as both of us go to work, she now feels on the same level that she goes to work, too, and has a job. She often says, 'Well, I have to go to work tomorrow.' It's a tremendous boost for her self-esteem. I don't know what we would have done if we hadn't found Prime Time. Our only other alternative would have been to find a sitter, and I don't think that would have made her happy. She enjoys being with the ladies. They're getting to be sort of friends now and that's important to her. I think a sitter would have been our only alternative and I don't think it would have worked."

Joyce added, "No, because the Center gives her a sense of independence. She feels she isn't dependent. I think if someone came in and sat with her it would make her feel that she was really at the end of the line. I don't know any other way that we would have dealt with it because she could not have been alone really very much longer. It's just been very gratifying. And we're very grateful for the program. It's been super. It certainly is a wonderful thing. It's done so much, and I'm sure it's done equally as much for the other ladies that are here because I think Mother is one of the oldest ladies here, as I'm sure it's done as much for them."

The following is an effort to define the concept of day care:

Modality	Major service objective	Type of client	Service setting
Community care program.	To provide the services and programs necessary to prevent long term institutionalization; i.e., meals on wheels, outreach, friendly visitors, transportation, in home health care, legal aid, counseling.	Individual with medical or cognitive impairments that would not allow them to leave their home. Individuals whose overall capacity for independent functioning would not be possible without these supports.	Specialized senior center nursing homes, social service agencies, and free standing facilities.
Crisis center	To provide a protective environment to assist the individual in coping with their specific problems and situations.	Individuals with acute cognitive or functional psychiatric problems not requiring medical management.	Psychiatric hospital, nursing home, or free standing facilities.
Chronic care day center.	To assist the individual to achieve and maintain the maximum level of functioning. This would include a transitive, or protective environment that assists the individual and their family in dealing with the multiple problems of daily living.	The individual has acute or chronic cognitive, or functional impairments not requiring nursing or other medical supports.	Nursing homes or free standing facilities.
Day hospital	To provide care resources and medical supervision to help the individual regain an optimal level of health following an acute illness.	The individual is in active phase of recovery from an acute illness. They should be no longer requiring a twenty-four hour inpatient setting, but can benefit from the day services of a rehabilitation center.	Hospital, rehabilitation center, or nursing home.

Resource for the chart: Philip Weiler and Eloise Rathbone-McCuan, Adult Day Care, Community Work with the Elderly, Springer Publishing Co., New York, p. 7.

Submitted by Albert R. Siegel, MD., Principal Investigator, Adult Restorative Services, The E. S. Edgerton Medical Research Foundation, Wichita, Kans.

In small communities and rural areas, physically-disabled adults need an alternative to institutionalization. Day treatment can serve adults who continue to live at home. It can use existing personnel and equipment. Through an Administration on Aging Model Project grant No. 90-A-1620(01), "Adult Restorative Services," The E. S. Edgerton Medical Research Foundation is demonstrating the day treatment concept in four rural Kansas communities.

Local nursing home staff are trained to offer individually prescribed and group activities to chronically ill or disabled adults who come to the nursing home for day treatment, but live in the community. Participants and other community residents who do not take services are followed for 24 months for changes in physical condition. Evidence is sought of improvement, stabilization, or deterioration of ability to accomplish activities of daily living with a degree of independence which allows the individual to live alone or with family in the familiar community, retaining established ties and social roles. Restorative services are offered in cooperation with other social and health services.

Licensed adult care homes operate in small communities which may lack other health services, so establishment of restorative services in these existing facilities may be a practical means of offering restorative services for rural residents. Client treatment is reimburseable through some private insurance plans, Veterans Administration and Medicaid. Project staff have developed arrangements with Kansas Medicaid for clients determined to be medically and financially eligible who come into the treatment sequence with medical need.

Arrangements for reimbursement and definition of policies and procedures to meet reimbursement agency criteria have been very time consuming. We strongly urge communication between agencies and bureaus to eliminate some of the contradictory requirements. Medicare does not pay in an Intermediate Care Facility (ICF). It is important that medicare regulations be altered to pay in an ICF facility, thus eliminating the costly three-day hospital stay and the Skilled Nursing Home (SNF) requirements.

Current programs do not adequately reimburse organizational costs, especially in rural areas, for transportation and time spent in travel. (For one elderly couple, living 9 miles from the nursing home, the cost of gas for her therapy 3 times per week represents 9 percent of their total income. They do not have available discretionary dollars.)

State laws should require private insurance to cover home health, day care and hospice services.

Financial assistance, when proven necessary, should be available to families who wish to and will keep their aged at home.

There is a lack of alternatives to nursing homes. Home health, day care and homemaker services should be available to all aged. Each county should have these services.

This Adult Restorative Services project concentrates on making restorative services available in the home community which will improve quality of life for chronically ill and disabled adults who now do not have access to therapy or who must be separated from family and familiar surroundings in order to receive services. There is growing awareness of need for restorative services and concern for mechanisms for delivery as numbers of potential consumers increase in rural Kansas. Local citizens, professional organizations and State agencies may cooperate to implement similar services throughout the State if this project demonstrates that affiliation with existing licensed nursing homes is effective for the patient and practical financially. Rural Kansas' model of services affiliated with licensed nursing homes may be used in other states so there is potential for wide use.

SAINT JOHNS HOSPITAL,
Springfield, Ill., April 11, 1980.

Congressman CLAUDE E. PEPPER,
Chairman, House Committee on Aging,
Washington, D.C.

(Attention: Miss Lou Bracknell)

DEAR CONGRESSMAN PEPPER; In response to a suggestion from Edith Robbins, Division of Long Term Care, I wish to inform you of a program to sensitize medical students to the realities of aging in our community. The medical students of Southern Illinois University in Springfield, Illinois, as part of their rotation through Family Practice come to the St. John's Hospital Adult Day Care Center. As part of their conference, they are shown from examples of nursing assessments, completed in the home, medication profiles that blatantly reflect medication abuse and misuse in individuals before their entrance into the program. Realistic problems with activities of daily living that prevent integration with the community are discussed as well as the center's approach to helping the participant and his family minimize those problems by maximizing their abilities.

Our staff has observed that participants in the Adult Day Care Program have shorter and fewer hospitalizations then what had been reflected in their past medical histories. Although our participants have hospitalizations, they are frequently less acutely ill when diagnosed and frequently can be managed medically through the health care services of the program.

Prevention of acute illness, control of the effects of chronic illness, care planning and problem solving are vital components of our Adult Day Care Program. Involving the forty-five participants in the choice and decision making process has been beneficial to their mental and physical well being.

It is my hope that this information will be useful to you in testimony before Congress. Future legislation that recognizes the special needs—medical, social, emotional and psychological—of those over 60 could prevent growing statistics of socially isolated and physically disabled older persons.

Sincerely,

MARY JO SKUBE, R.N.,
Supervisor, Extended Health Services.

The New York Times

THURSDAY, MAY 15, 1980

Day Care Offers Option for Elderly

By LILIANE DROYAN KODNER

THE stroke was not fatal, but it left 66-year-old Jack Ritter in a coma, then severely paralyzed and unable to speak. After two years of rehabilitation in a nursing facility, a social worker advised Mr. Ritter that he could return home and continue treatment as an out-patient.

It was then that his wife learned of the institution's adult day-care program, which would provide the necessary transition between 24-hour nursing home care and community living.

"The day center has been wonderful for my husband," said Mrs. Ritter from their Brooklyn apartment. "He can be home again, talk to his friends, and still get physical therapy and meet new people."

An 82-year-old man who lives with his wife in their Bronx apartment was becoming increasingly confused and forgetful. His 78-year-old wife, who suffers from arthritis and a heart condition, felt isolated and unhappy about her husband's frequent depressions. Their daughter, who lives with her family on Long Island, did not want to place her father in a nursing home, but was unaware of available options.

She learned from a geriatric center in her parents' neighborhood that its day-care program could provide her father with professionally supervised group activities that would keep him alert and socially involved; her mother could receive needed long-term health care. The program would also arrange for a part-time aide to give assistance in their apartment.

"Day care has made a tremendous difference in their lives," the daughter said. "Dad couldn't function at all — now he's smiling again. Mom's conditions are being treated, and she's more interesting and happy because her mind is being used. I don't have to go to sleep worrying about them anymore."

Because of the high cost of nursing home care and the human consequences of institutionalization, interest has grown in finding ways of caring for infirm older adults in their own neighborhoods. Adult day care, an idea borrowed from England and Scandinavia, is one of the newest community programs being developed to increase the choices available to older people who can no longer live on their own.

Adult day-care centers, also known as day hospitals and a variety of other names, are attached to nursing homes or hospitals. The programs are aimed at shortening a hospital or nursing home stay, like Mr. Ritter's situation, or preventing institutional placement, like the couple from the Bronx.

The day-care centers provide one-stop medical and nursing care, rehabilitation, social services, recreational activities and hot meals, as well as round-trip transportation from home to center. Participants attend anywhere from three to six hours daily, one to five days a week, depending on individual needs. While no two programs are alike, they share similar goals of preventing physical and mental decline and teaching self-care skills to promote continued independent living.

"An older person's ability to remain independent and function at the highest level of health primarily depends on available community resources," said Dennis Kodner, director of planning and community services at Metropolitan Jewish Geriatric Center, which sponsors a day hospital. "Day care is an especially promising alternative for many aged people who need long-term care," he said.

According to the Health Systems Agency of New York City, there are more than 40,000 elderly persons in nursing homes in and around the city. A report issued by the Congressional Budget Office suggests that from 10 to 30 percent of those institutionalized do not need 24-hour nursing supervision, but can be adequately cared for in their communities.

A major problem with adult day care is financing. Medicaid, the state-administered program for the medically indigent, accounts for the greatest source of funding for this service in 14 states, including New York. In most cases, the state pays the entire cost of the program, for those who are eligible. Medicare, Federal medical insurance for anyone over 65, limits payment for specific treatments provided by the day-care center. Individuals not covered by either of these public programs may find that the cost of day care — though less than nursing home care — may be beyond their private means.

Senator Bob Packwood, a Republican from Oregon, plans to introduce a bill to expand adult day care and in-home services to all disabled persons and those 65 and older. Jeff Lewis, an aide to the senator, said the bill would combine all noninstitutional care into one comprehensive system and would eliminate existing financial barriers. The proposal, expected to be introduced before May 20, will be called the Community-Based Long-Term Care Act, he said.

Financing and Programs

Medicaid: Financially and medically needy individuals may qualify for day-care services without charge if income and assets are below state minimums. For information on eligibility and the address of a Medicaid office near you, call the New York City Human Resources Administration, 594-3050.

Medicare: The Federal health insurance program for individuals over 65 does not recognize day care as a separate service. However, under Part B (medical insurance), it pays part of the bill for physician services, therapy and other skilled care provided to patients in need of active rehabilitation. For information: local Social Security offices and adult day-care centers.

Insurance and Private Payment: Insurance companies may reimburse certain out-patient medical services rendered by adult day-care centers. For information, call or write your insurance company. Individuals not covered by either public or private insurance may be eligible for payment on a sliding scale or a full or partial grant. Out-of-pocket costs may range from $25 to $40 a day for the program. For information, consult the adult day-care center.

Adult Day-Care Centers

Jewish Home and Hospital for the Aged Day-Care Program, the Bronx, 290-5000.

Metropolitan Jewish Geriatric Center Day Hospital, Brooklyn, 853-2600.

Montefiore Hospital and Medical Center After-Care Program, the Bronx, 920-4172.

Mosholu-Montefiore Day-Care Center, the Bronx, 881-8084.

Peninsula Hospital Center Rehabilitation Division, Adult Day-Care Program, Queens, 945-7100.

Future Programs

Additional programs that have been approved in New York City and are scheduled to open over the next several months:

Beth Abraham Hospital, the Bronx, 920-5881.

Daughters of Jacob Geriatric Center, the Bronx, 293-1500.

Eger Nursing Home, Staten Island, 979-1800.

Jewish Institute of Geriatric Care, Queens, 343-2100.

Mary Manning Walsh Home, Manhattan, 628-2800.

The Hebrew Home for the Aged at Riverdale, the Bronx, 549-8700.

THE NEW YORK TIMES, THURSDAY, MAY 29, 1980

Letters

On Adult Day Care

TO THE HOME SECTION:

Liliane Dreyan Kodner's article ["Day Care Offers Option for Elderly," May 15] made a clear and intelligent case for the adult day care alternative.

I am pleased to note that the day care option has been coming into its own in Connecticut. It was identified in the findings of the Governor's Blue Ribbon Committee to Investigate the Nursing Home Industry in Connecticut, which I chaired in 1975-76, as a promising prospective component of the wide ranges of services provided the elderly. A pilot program set up in Norwich has shown the cost-effectiveness, as well as the human benefit, of adult day care.

Since that pilot program was concluded last June, the state has seen the establishment of 17 adult day care programs, now serving some 370 clients. The cost comparisons offered by the Norwich program were stark: $113.87 a week per client in total public cost for day care, against an average weekly per-client cost of $226 in a skilled nursing facility. The social advantages, of course, cannot be measured in dollars and cents: the comfort and relief of familiar surroundings; the elimination of unnecessary disruptions of personal and family lives; a general easing of tension and anxiety.

The great problem confronting the proponents of adult day care nationally is the terrible inadequacy of government support. As Miss Kodner pointed out, Medicare pays for only a fraction of the services provided through day care centers. And when older citizens are unable to gain access to or reimbursement for such community-based services as day care, they often find themselves with no alternative to institutionalization, in which their expenses will be fully covered by Medicaid.

In the months ahead, I and several of my colleagues on the Select Committee on Aging will press forward in our efforts to expand Medicare reimbursements for adult day care services, and to promote the creation of a new office for adult day care in the Department of Health and Human Services.

WILLIAM R. RATCHFORD
United States Representative
Fifth District, Connecticut

LARRY J. HOPKINS
6th District, Kentucky

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Congress of the United States
House of Representatives
Washington, D.C. 20515

July 11, 1979

Honarable Joseph A. Califano, Jr.
Secretary
Department of Health, Education and Welfare
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Secretary:

We are addressing this letter to you to express our deep concern for the Federal response to the elderly and their families in need of adult day health facilities as an alternative to institutionalization.

The Select Committee on Aging conducted hearings in Lexington, Kentucky, on July 6th to assess the Federal response to the health, economic, education, and social service needs of the urban and rural elderly. Those who testified on alternatives to institutionalization, cited adult day care programs, in Kentucky, as a humane and cost effective supportive service.

The two Centers for Creative Living in Lexington were pioneer projects in this field, and received Medicare reimbursement during the HEW pilot program mandated by P.L. 92-603. Medicare funding has been discontinued, however, and through lack of funds the program is now threatened to the point that the two centers have been forced to merge into one, and to curtail services. Witnesses at the hearing on July 6th emphasized the success of this program in meeting their needs and stressed that more innovative adult day health care programs of this type are needed to fill the gaps in the health care continuum in Kentucky.

We would like to request that you review and advise us on the current Department policy on reimbursement of adult day care under Medicare.

Further, we would recommend that a focal point be established within the Department to coordinate the myriad of health and social service funding sources that may be utilized for adult day care, with the goal of providing a clearinghouse for the dissemination of information and technical assistance to State and local agencies and centers which seek to establish or maintain day care programs.

Finally, please advise on recommendations for legislation to support adult day care.

Any additional information or assistance on adult day care and realistic funding options for programs such as the Center for Creative Living would be appreciated.

Thank you in advance for your assistance.

Sincerely,

Larry J Hopkins
LARRY J. HOPKINS
Member of Congress

Claude Pepper
CLAUDE PEPPER
Chairman, Select Committee
on Aging

CLAUDE PEPPER, FLA.
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LOUISE BRACKNELL
STAFF DIRECTOR

U.S. House of Representatives
SELECT COMMITTEE ON AGING
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE
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[illegible]

JAMES ABDNOR, S. DAK.
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MARC L. MARKS, PA.
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HAROLD C. HOLLENBECK, N.J.
ROBERT (BOB) WHITTAKER, KANS.
CHARLES E. GRASSLEY, IOWA (EX OFFICIO)

LARRY S. PARKINSON
MINORITY STAFF DIRECTOR

April 4, 1980

Dear Friend:

Your assistance is requested in a matter of concern to the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging.

On April 23, 1980, the Subcommittee will conduct a hearing in Washington, D. C., on the subject of adult day care. Preparatory to that hearing, we have developed a survey for the purpose of collecting information concerning adult day care programs in the States.

We would deeply appreciate your cooperation in completing the enclosed survey and returning it to our offices by April 15. It is likely that the information requested is maintained by different persons in State government. It would be most helpful if you could designate one person in your Agency to act as the coordinator of responses to this survey. In cases where a precise response is not possible, please supply estimates and so indicate.

Survey responses should be addressed to the Subcommittee on Health and Long-Term Care, U. S. House Select Committee on Aging, Room 715, House Annex No. 1, Washington, D. C. 20515.

Many thanks for your willingness to be of assistance in this important endeavor.

Kindest regards, and

Sincerely,

Claude Pepper
Chairman

Jim Abdnor
James Abdnor
Ranking Minority Member

Enclosure

ADULT DAY CARE SURVEY
Subcommittee on Health and Long-Term Care
U. S. House Select Committee on Aging
April 4, 1980

Please respond to the following questions by April 15. Where exact responses are not possible, please give estimates and so indicate. Your cooperation and assistance are most deeply appreciated.

1) a. Are adult day care services provided in your State? _____Yes_____No

b. If so, how many programs are there? ____________

c. Is this number estimated or exact? ____________

2. a. How is adult day care funded in your State?

State Plan for Medical Assistance (Title XIX) _____Yes_____No

Title XX Plan (social services) _____Yes_____No

b. Of the following potential sources of funding, which have been identified, which have been used in your State to develop or pay for adult day care programs? (Please check.)

_____Title XVIII, Social Security Act (Medicare)

_____Title XIX (Medicaid)

_____Title XX (social services)

_____Title III, Older Americans Act

_____Mental Retardation Facilities and Community Mental Health Centers Construction Act, Titles I and III

_____Health Revenue Sharing Act, Titles I and V

_____Education Acts

_____Domestic Volunteer Service Act

_____Community Services Act, Title II

_____Comprehensive Employment and Training Act, Titles I,II, and VI

_____Urban Mass Transit Act

_____Housing and Community Development Act, Title I

_____State and Local Fiscal Assistance Act

c. How much will be spent for adult day care in the current fiscal year in your State? If possible, please break down among the various funding sources.

3) List all services provided through the adult day care programs in your State and designate by (*) which are the most commonly provided. Please indicate which services are covered by Medicaid (Title XIX), Medicare (Title XVIII), social services (Title XX), or the Older Americans Act, Title III.

4) What is the average cost per client:

_______ per day ________ per month _________per year

5) Has the State established statewide admission or eligibility criteria under this program? If so, what are these?

6) Please provide statistics for the following, in the form of an annual report, if possible.

a. age range of adult day care clients ____________
b. median age of clients ____________
c. mean age of clients ____________
d. types of physical or mental handicaps

e. total number of clients served ____________annually __________at a given time

7) How many persons would you estimate to be in need of adult day care in your State? __________

On what information do you base this estimate? Please describe the results of any surveys or studies which have been conducted in your State with regard to the need for adult day care or community-based long-term care in general and attach any pertinent materials.

8) a. How many persons could be diverted from nursing home care if adult day care were fully funded in your State? ______________

b. With full funding for adult day care, could persons who currently reside in nursing homes return to their own homes or communities?

_____Yes _____No

If so, how many would you estimate? ______________

9) a. Does your State have standards for adult day care? _____Yes _____No

b. If so, are the standards for _____funding _____ licensure _____both
Please attach a copy of these standards.

10) What other services such as transportation would be necessary for day care to be successful in your State?

11) In your view, what are the most significant barriers to the development of adult day care as a full-fledged component of a "continuum of care?"

12) a. What is the per diem Medicaid reimbursement rate (or range) in your State for care in:

SNF (skilled nursing facility) ______________

ICF (intermediate care facility) ______________

Other (please indicate level of care) ______________

b. What is the average daily census of nursing home residents in your State? Please list by SNF, ICF, or other.

13) Has your State undertaken an analysis of the cost benefits of adult day care programs? If so, please cite findings. If not, has a consensus developed regarding the cost benefit of adult day care?

14) a. What procedures have been developed by your State to approve the operation of adult day care centers which provide services covered under Medicaid?

b. To what extent has adult day care been considered in the State health plan as a way of meeting the long-term care needs of the impaired elderly?

15) Please list and discuss any recent developments or pending plans or proposals in your State with regard to the development of adult day care services for the elderly.

16) Please attach a short summary or history of any cases which demonstrate significant improvement in the functioning status or living situation of older persons as a result of the availability of adult day care.

Prepared by Janice A. Lamb

ADULT DAY CARE SURVEY RESPONSE ANALYSIS
September 23, 1980

This analysis was performed based on the responses received from an adult day care survey developed and administered by the House Select Committee on Aging, Subcommittee on Health and Long-Term Care in preparation for a hearing held on the subject on April 23, 1980. Questionnaires were mailed to every Medical Assistance Office in each of the fifty states, plus Puerto Rico, Guam, the Virgin Islands, and the District of Columbia. Out of 54 questionnaires, responses were received from 32 states for a response rate of 59%.

A regional analysis conducted for any possible response bias showed that caution will have to be exercised for any generalizations or conclusions to be drawn from this survey as the South and West tend to be more heavily represented, while states in the Mid-Atlantic and Central regions showed only meager response rates (40% and 41% respectively). 50% of the states in the New England region responded, while there was no response from any of the territories surveyed.

Bearing the above cautions in mind, the findings of this survey are as follows:

Four states, Alaska, Colorado, Oklahoma, and Wyoming, responded that they had no day care programs, and were, therefore, omitted from most of the total response counts. Of the 28 remaining states, the total number of programs reported was 799, but within this number, the range varied from 1 - 204.

Only 25% (7) of the states fund day care through a State Plan for Medical Assistance, while 93% (26) of the states use Title XX funding, including the seven states also using Title XIX. Title III of the Older Americans Act and general state and local funding were the third most popular sources of funding (57% each).

The most frequently provided service listed by the states in their day care programs was nutrition (89%) followed by social services (86%), health services (75%), and transportation (71%). For a complete listing, please see attachment.

The average cost per client ranged from $5.30 (Georgia, Title XX services only) to $37.50 per day for Utah mental health day care services. The mean per day for 26 states responding was $14.03, the median was $15 per day.

As to the characteristics of clients being served in adult day care programs, the age ranges most frequently reported were for 60+, closely followed by programs serving ages 18+. The most frequent median ages reported were 75 and 78 though few states answered this question. Heading the list for types of handicaps of clients served were mental disorders (46%), heart disease (43%), stroke (32%), and arthritis (32%). A complete list may be seen in Attachment A.

The number of clients served annually varied widely from 25 (Idaho) to 2,500 (Florida). The mean for 24 states responding to this question was 595. The mode, however, probably reflects a more accurate picture and shows figures in the 200's most frequently cited. Number of clients served at a given time ranged from 11 (Idaho) to 1,700 (Massachusetts and Florida). The mean here was 420, while the mode showed that the categories 10-99 and 100-199 contained the most frequent number of observations.

Estimated population in need of adult day care per state ranged from several hundred (Idaho) to over 70,000 (Georgia). However, only 11 states report having done any kind of survey or study with regard to the need for day care.

Claims as to the number of persons who could be diverted from nursing homes also varied widely. Guesses ranged from 50 individuals (Alaska) to 90% of the potential nursing home population (Pennsylvania). However, with full funding, 93% of the states thought they could return current nursing home residents to their communities. Estimations as to how many persons this would affect also varied from the frequent response of unknown to guesses of up to 50% of the nursing home population.

With respect to standards for adult day care, 50% (14) of the responding states have standards for funding, 39% have licensure standards, and 21% have standards for both.

For day care to be successful, 46% of the states listed transportation, 25% listed additional medical services, and 21% additional nutrition services as necessary service additions.

Present barriers to the development of adult day care were listed as: funding by 93% of the states, community awareness by 18% of the states, and transportation and trained staff were mentioned by 14% of the responding states.

Per diem Medicaid reimbursement rates for SNF's ranged between $16.20 (Georgia) to $59.16 (New Mexico), though the average rate equalled $35.43. The ICF rates ranged from $14.60 (Nebraska) to $41 (Rhode Island) with a mean of $27.52.

Daily census of nursing home residents for SNF's ranged from 80 (Iowa) to 17,532 (Massachusetts). The mean was 4,794.8. In ICF's, the daily census ranged from 122 (California) to 28,476 (Massachusetts). Thus, the mean was 10,069.6. (It must be pointed out that none of these mean figures is a very accurate reflection of what the reality probably is, as the response rates for this question were again very low.)

A cost benefit analysis of day care has taken place in only four states: California, Connecticut, Florida, and Texas. A majority of the states reported having no cost benefit analysis results and only 29% report any kind of consensus regarding day care has been reached.

Of the seven states providing Medicaid services in adult day care centers, six(6) of the states have state issued standards and regulations that must be followed by all providers. Generally, AAA's, Medicaid Offices, and Review Teams monitor compliance. Nebraska has standards for out-patient claim basis only. Two states, Florida and Connecticut, are in the process of developing procedures.

Ten (10) states do, however mention adult day care as a specific part of their State Health Plan and at least five states are making plans to try to secure Medicare/Medicaid coverage for day care services.

Conclusions

In summary, the simple fact that Texas alone has 204 adult day care programs compared to only three years ago when the Directory of Adult Day Care listed only approximately 300 programs available in the entire United States, attests to the current popularity and growth of these programs despite minimal Federal assistance in their development and lack of solid empirical evidence as to their effectiveness.

It appears from the survey that day care in this country is serving quite a variety of individuals with a variety of service options, supported mainly through Title XX and state and local contributions. It also appears that finding and maintaining funding sources is of great concern to many of the states and may explain why attempts to secure Medicaid/Medicare funding were often mentioned under the category of recent state developments.

In a time of increasing elderly population, high costs of nursing home and ICF care, it appears that day care is currently functioning as a needed alternative on the local level regardless of the eventual outcomes of further cost-benefit analysis.

ATTACHMENT A

ADULT DAY CARE SURVEY RESPONSES

1) Are adult day care services provided in your State?

28 states responded YES: California, Connecticut, Florida, Georgia, Hawaii, Idaho, Indiana, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, Minnesota, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Virginia, Washington, West Virginia.

4 states responded NO: Alaska, Colorado, Oklahoma, Wyoming.

32 Total Responses

b. If so, how many programs are there?

Out of 32 states, there was a grand total of 799 programs.
The range was from 1 - 204.
The median was 11.
The mode was 0 (closely followed by 7).
The mean was 25.

c. Is this number estimated or exact?

9 states gave estimations.

2) How is adult day care funded in your State?

State Plan for Medicaid Assistance (Title XIX):
25% (7) responded Yes: California, Georgia, Massachusetts, New Jersey Texas, Washington, Nebraska.

Title XX:
93% (26) responded YES.

Both Plans:
25% (7) same seven above.

b. Identify potential sources of funding.

28 Responses

93%	(26)	Title XX
57%	(16)	Title III
32%	(09)	CETA, Titles I, II, VI
25%	(07)	Title XIX
18%	(05)	MR/CMHC, Title 1, Title III
18%	(05)	Urban Mass Transit Act
18%	(05)	State and Local Fiscal Assistance Act
7%	(02)	Domestic Volunteer Service Act
7%	(02)	Health Revenue Sharing Act, Title I, Title V.
4%	(01)	Title XVIII
4%	(01)	Education Acts

4%	(01)	Community Services Act, Title II
4%	(01)	Housing and Community Development Act, Title I
57%	(16)	Mentioned some sort of general state/local funding
36%	(10)	Mentioned private funding

Idaho is entirely dependent on Title XX for funding.
California is using Title XVIII under Section 222.
Oregon day care is entirely funded by local and private funds.
Average of 3.82 funding sources used per state.

c. How much will be spent for adult day care in the current fiscal year in your State?

The most frequently cited sources were Title XX and Title III:

Title XX range: $2,998,605 (Pennsylvania) - $5,000 (Massachusetts) = $2,993,605.
Mean for 21 states: $640,396.66.

Title III range: $226,569 (Minnesota) - $31,735(Montana) = $194,834.

Other figures varied widely.

3) List all services provided through the adult day programs in your State.

25 Responses

89%	(25)	Nutrition
86%	(24)	Social Services
75%	(21)	Health Services (see breakdown)
71%	(20)	Transportation
68%	(19)	Recreation
50%	(14)	Educational Services
46%	(13)	Personal Care
46%	(13)	Referral Services
43%	(12)	Counseling
43%	(12)	Physical Therapy
43%	(12)	Occupational Therapy
39%	(11)	Speech Therapy
39%	(11)	Rehabilitation
14%	(04)	Outreach
11%	(03)	Assessments
7%	(02)	Advocacy

Various single responses included: remotivation, chore and homemaker services, training and self-help skills.

Health Services Breakdown

21 Responses

43%	(12)	Physical Therapy
43%	(12)	Occupational Therapy
39%	(11)	Speech Therapy

32% (09) Nursing Services
32% (09) Individual Health Plans
26% (08) Medical Supervision
18% (05) Emergency Services
18% (05) Medical Consultants
7% (02) Physician Services
7% (02) Podiatry Services
4% (01) Dental Services

(For unknown reasons, Florida, Iowa, and Virginia did not respond to the services question.)

4) What is the average cost per client?

Per Day - 26 responded.

Range: $5.30 (Georgia Title XX services only) - $35.70 (Mental Health Services in Utah) = $30.40.

Mean: $14.03
Median: $15.00

Per Month - 15 responded.

Range: $489 (Minnesota) - $106 (Georgia Title XX) = $383.00

Mean: $228.73
Median: $208.57

Per Year

Range: $6,292 (Washington) - $1,026.14 (New Mexico) = $5,265.86.
Mean: $2,943.46 (much of the information was incomplete)
Median: $2,544.85

5) Has the State established statewide admission or eligibility criteria under this program? If so, what are these?

68% (19) states have some sort of state criteria.
36% (10) mentioned Title XX eligibility requirements.
21% (06) mentioned Title XIX eligibility requirements.
7% (02) states are in the process of developing criteria.

6) Refers to the characteristics of clients served.

a. Age Range: Most frequently reported ranges were for the programs serving ages 60+, closely followed by programs serving ages 18+.

b. Median Age: Most frequent median age reported was in the 70's with 75 and 78 listed most. (Only 12 responded.)

c. Mean Age: In the 70's most frequently listed (12 responded).

d. Types of physical or mental handicaps:

23 Responses

46% (13) Mental Disorder (including emotional impairment)
43% (12) Heart Disease
32% (09) Stroke
32% (09) Arthritis
29% (08) Blindness/ Vision Impairments
25% (07) Hearing Impairments
25% (07) Diabetes
21% (06) Frail
21% (06) Mildly handicapped
21% (06) Depression
18% (05) Respiratory (emphysema)
18% (05) Hypertension
14% (04) Neurological Disorders
14% (04) Physical Deterioration
14% (04) Cancer
14% (04) Chronic Brain Syndrome
11% (03) Mental Retardation
11% (03) Parkinson's Disease
11% (03) Mobility
11% (03) Speech Impairments
7% (02) Social Impairments
7% (02) Amputees
7% (02) Chronic Impairments
7% (02) Epilepsy

Single responses included: paralysis, wheelchair patients, HCVD, high ADL rating, restoration needs and bladder/bowel impairments.

e. Number of clients served annually:

24 Responses

Range: 2,500 (Florida) - 25 (Idaho) = 2,475
Mean: 595
Median: 329
Mode: 200-299 category

Number of clients served at a given time:

22 Responses

Range: 1,700 (Massachusetts and Florida) - 11 (Idaho) = 1,689
Mean: 420
Median: 276
Mode: 10-99 and 100-199 categories

7) How many persons would you estimate to be in need of adult day care in your state? On what information do you base this estimate?

Estimated population in need ranged from several hundred (Idaho) to 70,213 (Georgia).
Mean out of 17 figures offered was 16,476.

11 States reported having study results.

8) How many persons could be diverted from nursing home care if adult day care were fully funded in your State?

a. Numbers vary widely from guesses of 50-100 individuals to claims of 50 and 90% of potential nursing home clients.

b. With full funding for adult day care, could persons who currently reside in nursing homes return to their own homes or communities?

93% (26) responded YES. Only Utah disagreed saying in question 16 that it is difficult to move people from an institution back into the community.

c. Estimates range from unknown (5) to 10,530 or 50% of the nursing home population.

9) Does your State have standards for adult day care? Are they for funding or licensure or both?

28 Responses

50% (14) of the States have standards for funding.
39% (11) have licensure standards.
21% (06) have standards for both.

10) What other services such as transportation would be necessary for day care to be successful in your State?

25 Responses

46% (13) Transportation
25% (07) Additional Medical Services
21% (06) Additional Nutrition Services
14% (04) Home Health Services
14% (04) Homemaker Services
14% (04) Psychiatric/ Counseling
11% (03) Additional Funding
7% (02) Housing
7% (02) Outreach
7% (02) Recreation
7% (02) Chore Services
7% (02) Telecare
7% (02) Personal Care
7% (02) Social Work

Other responses included: trained staff, appropriate facilities, weekend support services, I and R, etc.

11) What are the most significant barriers to the development of adult day care as a full-fledged component of a continuum of care?

26 Responses

93% (26) Funding
18% (05) Community Attitude/ Awareness
14% (04) Transportation
14% (04) Trained Staff
11% (03) Start-up Funds
11% (03) Client Acceptance
11% (03) Lack of Knowledge
7% (02) Facilities
7% (02) Third-party Coverage
7% (02) Rigid/confusing Regulations
7% (02) Lack of State Licensing

Others included: philosophical differences, high per person costs, lack of appropriate definitions, etc.

12) What is the per diem Medicaid reimbursement rate in your State for care in:

SNF

Range: $59.16 (New Mexico) - $16.20 (Georgia) = $42.96
Mean: $35.43
Median: $34.95
Mode: $35.00

ICF

29 Responses

Range: $41.00 (Rhode Island) - $14.60 (Nebraska) = $26.40
Mean: $27.52
Median: $26.11
Mode: $26.00 approximately

Other types ranged from $15 cap on rest homes in Massachusetts to $80 for ICF/MR's in Iowa.

b. Average daily census of nursing home residents in your State?

SNF

Range: 17,532 (Massachusetts) - 80 (Iowa) = 17,452
Mean: 4,794.8
Median: 2,225
Mode: 11,000 - 12,000 range

ICF

20 Responses

Range: 28,476 (Massachusetts) - 122 (California) = 28,354
Mean 10,069.6
Median: 8,498
Mode: 3,000 range

13) Has your State undertaken an analysis of the cost benefits of adult day care programs? If not, has a consensus developed regarding the cost benefit of adult day care?

24 Responses

79% (22) states have no cost benefit analysis
14% (04) have conducted analysis
7% (02) in progress

43% (12) no consensus
29% (08) consensus is cost beneficial

14) What procedures have been developed by your State to approve the operation of adult day care centers which provide services covered under Medicaid?

24 Responses

6 states have state standard/regulations that must be followed by all providers; AAA's, Medicaid Offices, and Review Teams monitor compliance with regulations.

1 (Nebraska) has standards for out-patient claim basis only.

2 States (Florida and Connecticut) are in the process of developing procedures.

b. To what extent has adult day care been considered in the State Health Plan as a way of meeting the long-term care needs of the impaired elderly?

36% (10) states said it is a specific part of their State health plan.
32% (09) said it is only a minimal consideration or none.
25% (07) mentioned considering expansion of services or availability.
4% (01) state (Washington) has recommendations in draft.

15) List any recent developments or pending plans in your State with regard to the development of adult day care services for the elderly.

23 Responses

18% (05) Attempting to secure Medicare/Medicaid coverage.
14% (04) Working on legislation for day care licensing or developing standards.
11% (03) have pilot projects under consideration.

11% (03) Attempting to develop additional programs.
11% (03) Want to expand Title XX coverage.
7% (02) Have Long-term Care Task Forces investigating alternative services.
7% (02) Gave day care low priority and have little hope for expansion.

Others mentioned: Virginia Institute of Adult Day Care, provision for start-up funds, and development of long-term care plans.

*Note: Questions having fewer than 22 states responding, i.e. 20% of the data is missing, must be viewed cautiously as the validity and reliability of the remaining results becomes questionable at this point.

ADULT DAY HEALTH CARE - A CONFERENCE REPORT

Arlington, Virginia, September, 1977

Tucson, Arizona, September, 1978

This Project was Supported by

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OASH

Prepared by Brahna Trager

May, 1979

FOREWORD

The National Center for Health Services Research awarded a Conference Grant to the Department of Public Administration of the University of Arizona to conduct a National Conference on Adult Day Care. The Conference provided a forum for discussion and debate on the present state of knowledge and future directions that should be taken. Participating in the dialogue were a selected group of researchers, practitioners and policy makers actively involved with or concerned about this newly emerging alternative in long-term care.

The conference report on Adult Day Health Services, based on the recommendations of the Conference participants, provides provocative ideas about the perceived role of the services, the settings in which they should be offered, their place in the health care system, and the role of the Federal government in relation to program development. The views and recommendations contained in this report are those of the Conference participants, and no official endorsement by the National Center for Health Services Research is intended or should be inferred.

We are particularly grateful to Brahna Trager, who translated the lengthy lists of recommendations emanating from the specialized subject groupings into the well-ordered comprehensive report of the Conference findings.

We appreciate the generosity of the Health Care Financing Administration in permitting Mrs. Edith G. Robins to continue with her role as Project Officer after her transfer to HCFA. Mrs. Robins' dedicated leadership coupled with her comprehensive knowledge about adult day health services added greatly to the total effort.

We thank the Administration on Aging for providing the consultative services of Mrs. G. Sandra Fisher, and for supplemental financial support. And our gratitude is extended to the many participants who served on special committees, led task forces, and shared their expertise in all aspects of this complex endeavor.

In view of the growing concern about the need to establish viable, acceptable community-based alternative forms of care, this report, representing the opinions and recommendations of experts, should serve as a valuable additional resource in the field of long-term care.

Theodore H. Koff, Ed.D.
Principal Investigator

ACKNOWLEDGEMENTS

The Adult Day Health Care conferences would not have been possible without the thoughtful planning and constant encouragement provided by Edith Robins. Mrs. Robins also contributed substantially to the critical editing of this report.

Theodore Koff, Ph.D., who was Principal Investigator for the conference grant, provided the expertise essential to the coordination of the entire effort, ably assisted by Deborah J. Monahan whose unfailing and effective response to all of the exigencies of such an effort was invaluable.

The special efforts of the members of the Tucson Conference in pre-conference papers, in thoughtful discussion of program areas and in critical evaluation of this report were exceptionally productive.

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INTRODUCTION

Adult Day Health Care Services have become an important community resource. The population in need of these services is characterized as vulnerable, at risk, dependent or semi-independent, usually because of the presence of disability or impairment. The need arises when chronic impairment and a combination of physical and social circumstances threaten the individual's capacity to function in a personal environment and place unusual and, at times, insupportable pressures in self-care and caretaking responsibilities on those who are concerned.

The number of elderly persons for whom advancing age has brought severe disability has become significant in the population of the U.S. Analysis of service utilization by this group with its multiple needs indicates that use of the resources which are inappropriate and unnecessarily costly may occur in the absence of appropriate care. This trend has stimulated interest in the development of community services which offer care, sometimes of long duration, and of good quality, in order to sustain personal choice for continued life in the community, and at the same time contain precipitously rising costs. (Younger adults whose impairments may have occurred in childhood or early life are in many ways affected by similar pressures and have similar needs.)

Admittedly, it is difficult to define or delineate the population now described as those in need of long-term care since many acute care needs are also inappropriately met, and many chronically-ill persons require substantial care only during episodes of acute illness. Nevertheless, it has been generally agreed that the development of non-institutional community care resources has become important in an effective social-health delivery system. Although three-fifths of the population over 65 have no chronic conditions that affect their usual activities, there are almost four million non-institutionalized older persons in the United States who are severely limited because of chronic illness. Another four and one-half million non-institutionalized older persons are restricted in the amount or kind of activity they are able to perform.1/Concern for the health status of this population has been accompanied by awareness that sharply rising health costs must be viewed in the context of cost-quality effectiveness. Increases in hospital beds, in nursing home beds and in utilization of these and other health care resources have raised questions about inappropriate resource development and, as a consequence, about expenditures which may be excessive because care that is related more closely to need and is more responsive to community choice is not available.

The concept of community care systems or "networks" of non-institutional services directed to safe maintenance of individuals in the community and in the personal environment has grown in theory, if not proportionately in substance, since the 1950's. Recognition of the need for continuity in care, services which include such resources as Home Health Care, Meals-on-Wheels, Congregate Meals Centers, Senior Centers and recreation and social programs, special transportation services, and, finally, Adult Day Health Care Services is increasingly evident. These services which have developed unevenly, both with respect to distribution and service scope in the United States, represent efforts to confront the fact that new approaches are required in order to provide for what has been described as a "community support system" -- a service sequence increasingly necessary in planning for long-term care, particularly for the elderly population. Projections indicate that there will be substantial increases in this population in the U.S. by the end of this century, a factor which gives added significance to the potential scope and intensity of the need for new approaches.

In the two conferences described in this report, Adult Day Health Care Services have been characterized as "an idea whose time has come." Conference members noted that "in spite of the ambiguities in funding and the absence of much-needed central resources for planning, guidance, coherent methodology and central leadership, there has been surprising growth in Adult Day Health Care programs over the last four years." In 1974, when one of the first of the studies of Adult Day Health Care Services was undertaken, fewer than 15 programs could be identified in the United States. In 1977, prior to the Arlington Conference reported here, a directory of Adult Day Health

Care programs listed 200. By 1978, at the time of the Tucson Conference, this number had grown to 300, and early in 1979, it was estimated that approximately 600 programs of varying quality and emphasis were in existence in the U.S. This escalating service growth within a relatively short period of time supports the conclusion arrived at by Conference participants, that Adult Day Health Care Services merit serious consideration and justify their inclusion in policy making, planning, funding and implementation of long-term care health-social resources in the U.S.

Purpose of the Report

This report has a dual purpose. It summarizes the proceedings of a two-part conference grant sponsored by the National Center for Health Services Research (PHS-DHEW). It is intended also to serve as a resource document for those who are interested in the present status of Adult Day Health Care* in the United States as it was reflected in Conference discussions.

ADULT DAY HEALTH CARE CONFERENCE

In September of 1977, the first of a planned two-part conference on Adult Day Health Care took place in Arlington, Virginia. More than eighty people representing providers, planners, policy makers, funding sources and related government and private service fields attended. Although the title assigned to the Conference was "Researchable Issues in Adult Day Care," the discussion ranged over all aspects of the field. In addition to a list of issues requiring clarification through research, the group effort produced questions, problems and recommendations, many of them central to the services, but not necessarily subjects for research.

The second part of the Conference took place a year later in Tucson, Arizona. Material produced in the Arlington Conference, because of its range, seemed to call for a more focused effort.

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* Throughout their development there has been considerable variation in the titles assigned to the services. This has contributed at times to misunderstanding of their content and purpose. The title, Adult Day Health Care, has been considered accurate and descriptive and is used in this report.

The format of the two conferences differed somewhat. The Arlington Conference heard presentations by providers representing different service emphasis and patterns of service delivery. Speakers also discussed major areas which are of concern to all service programs. This was followed by small group discussions, following the nominal group process, in which issues were ranked in the order of importance.

The Tucson Conference assembled a small group (nine members) representing different service specialties. This group reviewed the materials produced at Arlington and discussed in greater depth key areas of concern to those involved in Adult Day Health Care in any capacity. The goals of the discussions were intended to produce a document which would enhance the development of this relatively new care modality in the United States.

Focus of Conference Discussion

Because of the nature of the services and the level of their present development in the United States, clear definition of the subject areas presented in the Conference was difficult. There was a good deal of overlapping in discussions of the subject areas. It was recognized that a variety of factors might condition or affect the establishment of service purpose, of service emphasis, of the manner in which programs are organized, administered and delivered—the most important being the effect of funding and reimbursement sources on all areas.

The Conference discussions did, however, clarify many of the ambiguities which appeared to obscure elements considered common to all service programs. Information concerning the field in its present level of development and indications about future needs and future development emerged. Two subject areas appeared to be of overriding concern and interest: (1) the "models" concept which has been prevalent in Adult Day Health Care, and (2) the present funding situation as it affects the development of Adult Day Health Care as an appropriate care modality in the community care continuum.

Other discussion areas dealt with planning, organization and administration, delivery patterns (free-standing; multi-site; networks), and common areas such as staffing, training, quality assurance, and the virtually universal problem of transportation.

Conclusions which evolved from the discussions were in all cases tentative; the field is still too new to justify absolutes in any area of the services. Nevertheless, certain principles and convictions do appear to have a certain ring of "for-now-and-for-the-future-as-well." Primary among these was the principle that Adult Day Health Care is not a single service but a range of services provided in a variety of settings that represent part of the community care continuum, inextricably bound into the community support system--and that Adult

Day Health Care is a modality which offers an as-yet-unrealized (on a national scale), but invaluable, new resource to vulnerable populations for whom there is at present no care resource or none as potentially effective.

ADULT DAY HEALTH CARE "MODELS"

Many communities searching for a way of describing, limiting or defining their Adult Day Health Care Services have used the "models" concept which has evolved in the United States. Providers have tended to use the "models"[2] category or to have a "models" label assigned to their programs in order to indicate primary service emphasis, target populations and/or service combinations provided.

Categories which were developed initially classified centers as "Restorative", "Maintenance" and "Social." A fourth category was classified as "Mixed"---usually hyphenated to describe such combinations as "Health-Maintenance", "Maintenance-Social", etc.

The 1978 Directory of Adult Day Care Centers provided a guide for users which described three of the four models:

> Programs are classified as Restorative, Maintenance, or Social on the basis of information at hand.
>
> a. Restorative programs are those offering intensive, health-supportive services prescribed in individual care plans for each participant. Where prescribed, therapeutic services are provided on a one-to-one basis; constant health monitoring and psychosocial services are an integral

> part of the total program. Participants in the Restorative Adult Day Care program ultimately are discharged to a setting where less intensive services are provided.
>
> b. Maintenance programs are those with the capability (in terms of health professionals on the staff and appropriate facilities and equipment) to carry out a care plan for each participant. Services include health monitoring and supervised therapeutic individual and/or group activities, in addition to the psychosocial services.
>
> c. Social programs are those in which prime emphasis is on activities and lunches provided in a protected setting by a staff that does not include health professionals. In many instances, Social Day Care programs arrange for the delivery of health or health-supportive services outside of the Day Care setting and provide transportation to such services.*

These classifications have not been considered definitions. Guidelines for project grants funded under Section 222 of Public Law 92-603 mandating demonstrations and experiments for the purpose of testing Adult Day Care and Homemaker Services, described "a program of services provided under health leadership in an ambulatory care setting for adults who do not require 24-hour institutional care and yet, due to physical and/or mental impairment, are not capable of full-time independent living." The programs were to be directed to "meeting the health maintenance and restoration needs" of participants as well as providing socialization. They could serve either short-term or long-term need. Staffing required in the demonstrations included nursing; rehabilitation (physical therapy, occupational therapy and speech therapy) and provision for personal care; nutrition and social work services.

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* Programs listed in the 1978 Directory classified themselves: 9 as Restorative programs; 138 as Social programs; 78 as Maintenance programs. 35 programs classified themselves as Mixed Maintenance-Restorative programs; about 12 as Mixed Maintenance-Social programs. Puerto Rico summarized its services as totaling 65, of which one-half provided meals, recreation and other services usually considered standard for Social programs.

(This description of demonstration requirements resembles the Restorative model of Adult Day Health Care. As in many Adult Day Health Care centers, this resemblance was a matter of degree in project sites. There was a wide range in service intensity and in population characteristics in the projects.) 3/

In a report of a 1973 study of Adult Day Health Care, two "models" are described:

Model I or Day Hospitals were described as "having a strong health care orientation which exclusively sought to provide physical rehabilitation as a treatment goal...In its most health care-oriented form, it provides rehabilitative care to a selected group of individuals who show potential for improvement...In its less health care-, more socially-oriented form (Model II or Multipurpose), some programs eschew all but superficial health observation or custodial supervision and instead emphasize social interaction...Others my serve disabled populations which show little potential for rehabilitation but who require health supervision, custodial supervision, nursing services, assistance in activities of daily living, recreational therapy, social interaction and transportation."4/

The Restorative Model*

A restorative center is described as oriented to patients who are "in need of extensive rehabilitation---who would be in a skilled nursing facility if the center services were not available; who can be returned to self-care or shifted to lower-level services within an established time period." It is goal-oriented and time-limited (3½-4 months).

Centers which emphasize rehabilitation or restoration follow established patterns: in initial assessment in order to determine the participant's potential for achieving treatment goals; in provision of established treatment regimes; in review of plans and progress at established intervals. They tend to accept a higher proportion of wheelchair patients who are in the younger age ranges and maintain a relatively high staff-to-patient ratio with greater emphasis on the services of health professionals and on health care services. (The Trans-Century Report 5/ indicated that these centers served a relatively large group of stroke patients with multiple chronic conditions.)

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* The examples described are those presented at the Arlington Conference; they do not necessarily describe all centers which carry similar titles.

The Maintenance Model

An example of the Maintenance model is described as "not as staff intensive" as the Restorative model. All participants have an initial assessment. Reassessment of those in maintenance care is based on the expectation that service will be extended over longer periods of time than those in the restorative level. Maintenance services emphasize socialization, reality orientation, recreation, podiatry. The center uses the services of the Volunteer Improvement Program, drawing from its own clientele for volunteer services. (This service combination was described in the program example at Arlington; it may differ in other centers.)

The Social (or Psycho-social) Model

The example described is a center located in a retirement area. Originally established as a multi-purpose senior center intended to provide relief for families in which there is an elderly family member, within 1½ years the program evolved into a free-standing Adult Day Health Care Center. Its population is largely in the very elderly (84-98 age range), and consists primarily of people who live alone in hotels or small apartments. The major emphasis is on socialization. The program objective is to keep people in the community as long as possible. No direct health services are provided, although an RN directs the program and makes an initial home visit for assessment purposes. The group process is used extensively and effectively at the center, and participants play a large part in determining what the center program will be.

The "Models" Approach

A number of questions were raised concerning the categorization of centers, the "models" approach and the classification of the population served to fit these categories. These questions have been raised elsewhere and have been the subject of considerable discussion: Do these discrete categories fit the real service needs of populations in which there is a high incidence of impairment and disability with considerable fluctuation, both upward and downward, of individual health status? Movement to different levels of care may be required frequently and problems may arise when services in different combinations or of different intensity are not available under the same roof. It was suggested that the "models" concept might be considered an effort to skew services to funding sources - to provide services which can be reimbursed and/or to label them accordingly. The real difficulty which has led to service categorization might be found in inadequate funding and in the absence of a clear definition of the services. On the basis of present knowledge and experience, it appears that these arbitrary labels do not accurately describe the field of service and the population in need of Adult Day Health Care.

A more effective approach requires answers to the questions, "Who is Adult Day Health Care intended to serve?" and "What are its program goals?" While these questions cannot be answered definitively at this time, they can be dealt with in a broad framework which establishes the parameters of Adult Day Health Care. Areas requiring further enquiry and research can be delineated in order to clarify what should or should not fall within these parameters. There is, moreover, a body of knowledge available to the field although it may not yet be generally formulated.

Regarding the first question---the target population (Who is Adult Day Health Care intended to serve?). Potential consumers for whom Adult Day Health Care is appropriate may be found in the following population groups:

- the physically disabled or impaired elderly
- the disabled (young, old, long-term, short-term)
- the developmentally disabled (young, old, with varying severity of disability)
- all adults who have mental health problems associated with physical impairment.

The term "Adult Day Health Care" appears to establish the services as limited to adults and/or to the elderly. The younger age group for which Day Health Care programs offer many of the same services requires programs with emphasis on the special needs of children and young adults. The target population for adult services, therefore, includes the following groups:

- the developmentally disabled over the age of 21
- adults who are disabled as a result of trauma (stroke, accidents and other disabling events)
- the disabled or functionally impaired elderly (this grouping was cited as one which is numerically large).

The circumstances of need may vary considerably. Various combinations of need are found in all three subgroups---developmental disability, disability as a result of trauma, and disability which is the result of single or multiple chronic illnesses occurring as an adjunct to or as by-products of the aging process).

All of these populations could be considered potential candidates for Adult Day Health Care. Whether adequate and appropriate services are developed, however, depends upon policy and funding. (The terms "adequate" and "appropriate" are meant to qualify consideration of potential service use.)

Functional status within the three groups is considered a primary factor which qualifies potential consumers in the population for Adult Day Health Care. Functional status is further qualified by additional criteria:

- the intensity of the disability
- the quality of the disability.

Intensity is classified as minimum, moderate and severe along the scale of semi-independence to dependence in functional capacity.

Quality of disability as it relates to function is intended to describe the nature of the disability as it may affect special needs for care (related to factors which limit program capacity to provide needed care---incontinence, wandering, destructive or unpredictable behavior).

Linked to functional factors, and intimately related to them in assessment of service need, are adequate living arrangements---the quality and availability of an effective personal-support system.

> The presence or absence of people in the home is not a true indicator that there is a reliable resource in the home. For example, the presence in the home of working adults or children who are also disabled or otherwise limited in care-taking capacity may not constitute an adequate resource. The term adequate implies a reliable environment in the broadest sense.

The combination of functional disability and limitations in the personal support system comprises major elements in the criteria which identify the potential population for Adult Day Health Care services.

A third factor---the need for preventive services---was related to broad objectives in programming. Preventive intervention in order to control deterioration and excess morbidity is a general objective; it may, however, establish the need potential in selected population groups. Stereotypes which assume that "progress" in care is an absolute measure of program success and that the "outcome" of "goal-oriented" treatment will invariably achieve restored function may, in fact, ignore subtle processes which are also a measure of success. Such assumptions may affect community expectations and community support and deprive potential users of substantial benefits which cannot invariably be related to conventional measures of "outcome."

Mental Health Problems

Adult Day Health Care as a resource when mental health problems are present is affected by a variety of factors:

- The extent to which a center emphasizing a service mix (and a variety of problems in its consumer population) is able to integrate disoriented participants in the service group.
- The impact of people with mental health problems on attitudes of other participants.

Providers present a variety of attitudes and responses:

- Given a limited number of places in the center, the best use of both staff and facilities may be to allot those places to people who fit most closely into the center program. Although philosophically it may be desirable to have a center serving various diagnostic groups and various levels of need, it may become impractical and detrimental to the center programs to accept groups whose care needs do not parallel those of the larger participant group.
- Where there is a service mix and flexible admission policies, it is quite possible to accept and effectively serve people from mental hospitals or with psychological problems and to see positive results from their exposure to the center program. The proportion of such participants should not be too high; it may also depend upon the composition of the total participant group and staff willingness and capacity to accept and serve such participants.

- It is possible in a multi-service center to accept and serve a very wide variety of disabilities. With respect to organic brain syndrome, behavior of the individual is of great importance. People who are very confused and disturbed, or who are aggressive and destructive, or who have other problems which present difficuties in management such as a tendency to wander, may require a specialized service program---one that is more stable and routine which might be less stimulating and productive for other participants.

- Staff attitudes and the attitudes of other participants (apprehensiveness, depression) may affect the capacity of the center to accept and effectively serve this group. In a multi-level service center, too large a number of any one disability may affect the service balance. It is possible, however, given adequate staff and facilities, to develop sub-group activities for some portion of the participants, utilizing the core services for special needs as they become appropriate.

Problems arise when attempts are made to define the potential population in terms of mental health and/or mental illness:

- Serious questions arise when attempts are made to distinguish between candidates for the psychiatric day hospital and those for whom Adult Day Health Care would be most appropriate. There is a great deal of mislabeling in the mental health field, particularly in the older age ranges. Depression, apprehensiveness, anxiety, forgetfulness and seemingly marked dislocation in "normal" interaction may be the results of social isolation, limitations in physical functioning and trauma resulting from life style changes. In many of these situations, skillful assessment and treatment have produced marked reversal of seeming mental illness or organic brain syndrome.

- A distinction may also be made between mental illness without physical limitations and mental health problems with associated chronic illness.

("I don't know of anyone who is chronically disabled who does not have a mental health problem.")

Arbitrary exclusion of participants with mental health problems is neither feasible nor desirable. Problems of overlapping health, social and psychological status cannot be resolved by attempting to establish discrete service programs for each diagnosis. Distinctions can best be made by developing admission criteria in individual centers when purpose, staffing and service scope determine what groups can be effectively served. Such criteria are clearest when problems in behavior present overwhelming management and treatment problems (bizarre behavior which is upsetting to the center group; destructiveness, etc.), or when, on the other hand, they appear to be reversible or manageable within the scope of the service program. Diagnoses which may have arbitrarily assigned participants to such categories as chronic or organic brain syndrome, senile dementia, and all the various psychologically described personality states require careful assessment and service trials to determine their accuracy and the appropriateness of center services.

"We have all seen some of the most impressive functional gains from people who come to the center from mental hospitals. They are in the center, however, because the basic need is for physical care due to functional problems as well as social need."

The Potential Population Defined

A description of the populations for whom Adult Day Health Care could be appropriate and the general goals of the services is possible:

> Adult Day Health Care Services are most appropriate for dependent and semi-independent individuals whose physical and psycho-social needs have been assessed in depth by a qualified multi-disciplinary team of professionals who determine that effective services may be planned for the individual and family. Service objectives are to restore and/or maintain optimum health and functional status. Primary qualifying criteria are functional impairment or disability, qualified by the level and quality of such disability combined with or interacting with the availability and quality of the personal support system.

Adult Day Health Care is based upon a generic concept. There is room within the general framework for considerable elasticity in different programs with respect to selection of participant groups and the emphasis in the service program.

PATTERNS OF SERVICE DELIVERY

Delivery patterns in Adult Day Health Care vary. Free-standing centers may be single units in a given community. Services may be provided by more than one unit, each under separate auspices independantly administered.

Service delivery patterns have also been developed which rely on linkages of different kinds:

Satellite Programs

The multi-site or "satellite" organizational pattern is described as a chain of community Adult Day Health Care centers centrally administered but strategically placed in neighborhoods from which the participant population is drawn.

The example described at the Conference consists of six Adult Day Health Care Centers. It has the following characteristics:

- Responsibility for planning and evaluation is placed in a central office serving several service units in the community.
- Administrative services, budget and billing, purchasing, supplies, food, etc. are provided centrally to all units.
- Standards and program monitoring emanate from the central office for all units.

The central office also:

- Employs coordinators for the centers.
- Provides rotating specialized staff (physical therapy, occupational therapy, speech therapy).
- Provides training and staff development programs.
- Schedules transportation for all centers.
- Applies a staffing pattern which includes for each center:
  A coordinator
  A professional counselor
  A nurse
  A social worker
  Paraprofessional staff
  Staff (physical therapy, nursing treatment and other professional services).
- Serves population which includes all levels of ability and all age ranges. (Five of the centers serve participants who are sixty years of age and older; one serves the disabled in the younger age ranges). (Of the 115 participants served daily, 30% are in wheelchairs.) All levels of disability are served in all centers.

- Offers services which include a typical range of services provided by staff teams. (Professional services provided by the central office are scheduled in proportion to the treatment needs of participants at each site.)
- Provides well-developed transportation system which serves the participant groups in all centers and which also provides for special needs (physician-clinic visits, shopping and recreational transportation).

The example described is considered very efficient. Its advantages include maximum use of staff and transportation, provision of community-wide services which are uniform in quality and adapted to the neighborhoods in which the centers are placed, and great flexibility in staff assignments. The center staffs are highly motivated and carry full responsibility for the quality of their programs. Each center is responsible for its own intake, assessment and care planning. The central office intervenes only to monitor standards and provide assistance as necessary.

Satellite programs are not common. Their organization requires an integrated effort in community planning and support and a commitment to general service availability and standard service quality. Advantages in coordination are accompanied by an understanding by staff, participants and community of the goals of the community program.

Network Programs

These programs are usually planned and organized at the state level. The programs which operate in different communities may be dissimilar in some respects but have certain common elements and are dependent upon central planning.

An example of a state network contains 16 centers throughout the state. Services and staff are planned on the basis of the following assumptions:

- Older people have multiple problems and cannot be divided into target groups or disability areas; anyone the centers might serve in this age group is likely to have problems in more than one area.
- There is a need for participant "mix" in order to provide for interaction. People who are severely disabled physically may have no psychological limitations; those who have psychological limitations may function well physically. Emphasis on the help which participants are able to give one another as part of the total treatment program is necessary.
- People with multiple difficulties require a team treatment approach. The concept of models is not accepted because it tends to separate groups. Participant status at entry and changes in different areas of need may occur at different times in the course of treatment.
- Authority for care belongs with the participant who makes the decision about care plans which will best meet his needs. Case records are open and available to the participant. The services are goal-oriented and emphasize participant autonomy.
- The concept of the team approach is developed with the coordination of a "team manager" rather than a physician as a means of encouraging interaction. The community support systems vary. In the best, the center staffs work closely with public health nurses, Home Health Services, Meals-on-Wheels, etc.

Development of networks of Adult Day Health Centers throughout a state or portion of a state or region has advantages. The staff which is responsible for service quality develops considerable expertise. Admission criteria, services and administrative practices may be more consistent and equitable, and participants who meet criteria in one center may be more readily accepted in a center in another geographic area of the network when necessary. The standardized and consistent service pattern increases public understanding of the value and availability of the services. Standard procedures for reporting, data collection, guidelines which assure quality are more readily developed and increase accountability.

PLANNING, ORGANIZATION AND ADMINISTRATION

Planning, organization and administration in Adult Day Health Care Services have been profoundly affected by the absence of broad public policy with respect to these services as well as to all resources for long-term care. Inconsistencies in national and state action have impeded consistent service provision.

An important aspect of this absence of national leadership and of coherent planning has been the prevalent complexity in the array of funding sources, differing reimbursement methods, differing eligibility and service requirements throughout the field. The need in these areas of essential national policy---funding and program development --as reflected in the need for parallel efforts at the state and local levels was extensively discussed in conference sessions.

Planning

Effective planning for Adult Day Health Care Services at the national, state and local levels is dependent upon the recognition of these services as a part of the care continuum - an essential component in a much-needed network of community services. This in turn implies a perception of the need for other components in the community network without which Adult Day Health Care cannot function adequately.

Planning efforts should not be based upon the concept that Adult Day Health Care is exclusively or primarily an "alternative to institutional care," an idea which is difficult to eradicate in many policy-making and planning efforts (and in planning efforts for other needed community services such as Home Health Care, Homemaker Services, and special-needs transportation).

> - It is a great mistake to sell Adult Day Health Care of any kind as an alternative to institutional care. Undoubtedly, if Day Care were fully developed in a variety of models, some people could stay out of institutions. Most of the people who would be helped by Day Care, however, would not have any services at all without Day Care and they need these services desperately. If we sell the services as an alternative to institutionalization, policymakers and legislators will have unrealistic

> expectations and will be disillusioned. Day Care should be sold because it is a good program in all of its manifestations, and not as the mythical, magical alternative to institutionalization.

The alternatives issue was discussed from many aspects. The dangers of the "either-or mentality" in planning was stressed. Planning for Adult Day Health Care should be unrelated to planning for institutional beds.

A sharp distinction should be made between misguided efforts to develop the services as alternatives to institutionalization for cost containment purposes and a planning approach to the provision of day care services for the purpose of reducing inappropriate use of institutional and other resources. Provision of Adult Day Health Care Services will strengthen community systems, increase options for the community and widen the range of choices for individual consumers. The choice of services should be appropriate to the need. A wider range of options ensures such appropriate choice.

Planning must take into consideration the target population and the range of needs that it is possible for Adult Day Health Care to meet. Planning decisions are based upon the relation between these. Within the broad framework which may emphasize or combine different levels of care, service combinations and different approaches to service duration, it is essential that planning "avoid non-purposeful centers where people are just dumped or accepted with no agreement by the staff, participants, the family (or the planners) on what the expectations and goals are."

"To plan for Adult Day Health Care services, the goals of the service must be recognized by the planning constituency. The establishment of (community) need for the services within the array of community resources which are considered essential requires that specific functions be clearly defined. The identification of the target population...will help clarify the need for services. Designating the intake criteria will help to display how the service fits within the...support system."

An example of a planning effort stresses key elements which are essential to service development:

- Planning Stage - Reviewing the Field

  Prior to opening the Adult Day Health Care Center program, specialists on aging visited Adult Day Health Care Centers throughout the region and the U.S. and spent one year in the planning stage. They were concerned about the types of services they should offer, the types of facilities in which the centers should be housed, and the method to be used to transport participants to the centers.

- Developing Community Support

  Since the concept is a new one, a large group of community representatives (health care and social services providers and others with knowledge and interest in community services) was organized. Community support was therefore available to the planners.

- Establishing the Purpose

  After considerable discussion concerning population need, three major purposes were developed:

1. To improve and maintain the participants' level of physical, social and emotional function.
2. To prevent or delay institutional care by providing a resource which could enable the participant to live at home.
3. To provide relief to relatives who are employed, or who may be required to provide continuous care to a disabled family member.

- The Population Served

1. The center serves a population of which 80% of the participants are living in families in which both adult spouses (in the family) are employed. Situations in which the participant lives only with a spouse are those requiring care which cannot be handled by the spouse.
2. Most participants have severe physical impairments and many are on medication (50% in wheel chairs - 25% in walkers).
3. Most participants require special diets.

- Services Provided

1. Social and recreation activities.
2. Nursing and personal care including preparation and administration of medication; supervision of activities of daily living; supervision of personal hygiene.
3. Rehabilitation (only when reimbursed).
4. Social work - counseling and group work with participants and family members.
5. Nutrition services.
6. Emergency services.
7. Specialized transportation for all participants to all centers and to other community resources.

8. A Work Activity program (sheltered, paid employment).

- Setting

A decision was made that health facilities would provide the best settings because they are barrier-free, have kitchen facilities, available therapy, special bathing facilities. All centers are housed in nursing homes, but maintain their own staffs and are administratively separate from the institution in which they are housed.

- Projections

Planning envisions a senior center and a nutrition center level of service as well as movement in the core program toward greater emphasis on medical services in order to provide for greater continuity. This would also lay the groundwork for Medicaid reimbursement, and ensure future eligibility for participation in a national health insurance program.

- Special Aspects

Transportation

Participants are transported to other community resources included in the core plan in order to avoid the institutional "set" which can develop in day care and stimulate broader contact with the community. Transportation to and from the center and for other purposes is contracted for with a specialized transportation system. There are two specially equipped buses for each of three centers and all participants are transported. No participant is required to spend more than 45 minutes in travel.

Sheltered Work

The work activity program is provided through an arrangement with a sheltered work program in a rehabilitation center and has been an important center resource. About one-half of the center participants who have been in the work activity program ultimately go to a relatively full-time sheltered work (6 hours a day) in which they earn a small income.

"Planning requires not only goal identification, definition of service modality, and designation of the target population, but also a description of proposed implementation including funding and a method of evaluation or monitoring. The implementation process should indicate the physical facility to be used, the manpower required to staff the program, and the availability of both. A realistic description of anticipated funding sources should include steps taken and clearances obtained which will assure funding of the proposed budget."

Great stress is placed upon the importance of the relationship of Adult Day Health Care to other services. Community support is stimulated when important referral points are identified and reliable arrangements are made. This was described as a "marketing" or "packaging" approach, and emphasized concrete planning. For example, it is important that the community not be misled by casual assurances that referrals will come from hospitals unless there is a realistic expectation based upon transfer agreements and similar arrangements. A major element in planning is a systematic and continuous process of mutual education between referrer and referee. When valid referral sources and referral procedures have been established, there must also be a realistic understanding of what the services can and cannot offer. Interpretation of the services and their purpose ensures appropriate use of the services. The long-term care needs of the population are frequently so pressing that there is a tendency by referrer to "dump" problems on available resources, frequently without reference to their usefulness. This is a particular danger in Adult Day Health Services unless their precise function is understood.

Clarity in presentation of the services and their potential may affect community support significantly. The state, the community and the consumer may have various conceptions of the meaning of such terms as health, restoration, and social. They may also be limited in their understanding of the provisions in legislative, regulation and funding sources. Such misunderstanding can lead to unrealistic expectations.

Support from designated planning groups and groups whose membership or constituency may ultimately benefit from the development of Adult Day Health Care Services is essential - Health Systems Agencies, Area Agencies on Aging, mental health and mental retardation centers, and similar programs - play an important part in enhancing service development. Their involvement will ensure integration of this service in the community system and increase understanding of its place as an important unit in the long-term care sequence, broadening the range of available options (Day Care, Day Hospitals, Respite Care, Home Health Services, Senior Centers).

ORGANIZATION AND ADMINISTRATION

Considerations which affect organization and administration of the services in addition to those related to limitations in public policy were identified and consolidated into three major subject areas:

- Service combinations; their efficacy in maximizing resources and meeting consumer needs; the effect of state coordination on promoting services; manpower considerations.
- Development of needs assessment methodology, relationship of site selection and population need to continuum of care, and impact of eligibility standards on utilization.
- Promotion; development of acceptance of Adult Day Health Care as a modality of service delivery.

"In the human services arena there are...two classic questions which are continually being balanced in shaping public policy...: How can resources be maximized?; and, How can the needs of potential clientele be met?...Our collective experiences would probably suggest that the questions are frequently not clearly articulated or answered very systematically. One way of characterizing...is by discrete populations (i.e. physically impaired...handicapped... mentally impaired...by level of need). Another approach might be the functional level without regard to discriminating among client populations. In this array, particular clusters of professional staff would be elements of the continuum...different day care programs would take on the characteristics of the staff but serve a variety of clients...

"What is suggested here is that policymakers should work from an optimum continuum of care to an agency structure that will best support it, rather than the reverse..."

Federal-State organizational structure affects programs at the local level:

"When a poorly-perceived program is funded from the Federal level, the state implements it in whatever way is most convenient. Consequently, the service end which has had no impact on the first two decisions is forced to 'make do' with what is."

Problems are multiplied in the field at the delivery level and there is no central point at the Federal level from which assistance can be obtained.

"The field is begging for some help in the areas of organization and administration. [Providers] receive literaily hundreds of calls and letters asking for help with such questions as:

> How did you get ADHC written into your plan? It's not a recognized service. How did you get funding?
>
> How are problems with licensure dealt with?"

Guidance is not available at any point in the Federal structure, although by now there is a considerable accumulation of information which could be assembled and made available.

One of the best possibilities, if initiatives for integration at the Federal level are an unrealistic expectation, will be a movement to organize the field (providers, state offices, constituents, planners) to push for assumption of responsibility by the particular office or jurisdiction in which the problems in the field are best understood.

This central focus is needed in policy, program implementation, and in the crucial area of financing, in which the states are now the recipients of disorganized funding which then affects organization, administration and, ultimately, service effectiveness at the delivery level. It was recognized that while the variety of pressures at the Federal level could affect the choice and ultimate effectiveness of such a focus, it offers the best possibility for integrated effort. The demand for inclusion of both health content and social content in service provision accurately reflects the overlapping need for both services in the population and is one which might also have the best possibility for receiving serious consideration. There are rational ways to organize and structure services.

When there is consideration of a single agency (state or Federal), major emphasis must be placed upon the optimum range of service interests. Adult Day Health Care is possibly too small a program unit for a single structure. Long-term care, in which Adult Day Health Care is viewed as a significant program element, would provide a more comprehensive frame of reference for placement of broad service responsibility. For example, placement of responsibility in a single state agency which would have among its functions the establishment of an Adult Day Health Care program within the core long-term care system is best assumed in the context of continuity of care.

The structure should be broad enough so that the components of the system (Day Care, Home Health, Day Hospitals, etc.) are interrelated and geared to a population which is predominantly in need of the range of services which such a system would provide. The program should be broad enough to include all population groups in need of care and should not be limited to the aging. It should include those in need of long-term as well as short-term care.

For the immediate future, emphasis in such a program should be on non-institutional care since development of adequate and reliable community services will ultimately stimulate effective partnership arrangements for movement of consumers between all components of care, both those of the institution and those in the community.

EVALUATION, ACCOUNTABILITY AND RESEARCH

Considerations in planning lead inevitably to the information base required for its effectiveness. Similarly, programs which are developed require a reliable information base for evaluation of their impact upon the populations served and for measurement of the degree to which effort and financial investment are fulfilling community (in its broadest sense) intent.

The basis for acquiring necessary information for these purposes is usually a well-developed standard data collection system which will: (1) permit programs to evaluate their own performance over time; (2) provide a basis for comparison with other programs; and (3) ultimately contribute to the general acquisition of reliable information concerning the field. Such information provides objective support for policymakers, planners and service providers.

The Adult Day Health Care and the long-term care field in general have been handicapped by the absence of an effective and comprehensive data collection system.

The basic data set for long-term care which is being developed for general use by the National Center for Health Statistics has important implications for planning and evaluation in Adult Day Health Care. Unique aspects of long-term care which require analysis include those which indicate where people with long-term care needs are placed; how they move (or do not move) through the care system; legal status or guardianship (probably particular to the long-term care population). Data which measures client progress and evaluates program activity for cost-reimbursement analyses are assuming increased importance.

To produce a data source, the most effective record for Adult Day Health Care is one which combines both health and social material, reflecting increased understanding of the services as comprehensive.

In the development of Adult Day Health Care record systems, the basic record should be compatible with related records, i.e. those of nursing homes, hospitals and other community service records. Such compatibility would pave the way to achievement of an inclusive picture of the population and service utilization. It would answer questions concerning the relative usefulness of different services and identify populations for which they are most effective. It would indicate the results and ultimately the costs of service provision. The collection of basic data in no way implies that the facility should not keep such records as are essential to service needs of a given program. Careful planning should eliminate the duplication of records.

"To be beneficial and effective, systems must always be based on an analysis of the reasons for the need and demand for services. Otherwise, it is possible that good intentions will be harmful rather than helpful, particularly if attempts are made to solve non-medical problems with medical methods and techniques. The importance of medical factors can be overemphasized because individuals often mention medical problems first, this being easier and more acceptable. Of greater importance, however, may be underlying social and economic problems. The difficulties in developing a basic data set revolve around such problems as:

- The need for definitions which have not yet been established and are difficult to develop (What is a client? What is a visit?).

- The need for a data system which will be equally applicable to agencies of different size and staffs with different levels of skill.

- The need to design a data set which will distinguish between the various levels of care. (The range from restorative to social levels; how much service can be attributed to each.) The need for a method which will assess total client requirements and relate these to the supporting environment. (The "fit" between needs and environment.)

- The need to develop a data set which will provide a continuous record of the client as he/she moves from environment to environment (hospital, home care, day care, the long-term care institution, self-care).

- The need to develop a system of cost information which will make it possible to determine the true costs of care.

- The need to develop a method which will assess the population for whom day care is most appropriate, both for people in the community and for hospitalized or institutionalized persons.

- The need for a system which will offer a reliable base upon which providers can evaluate the programs they administer.

It is probably impossible to obtain this array of requirements for information from any single record or record system. There are, moreover, a number of policy questions which cannot be answered from a data system. The function of data collection is to establish basic information drawn from the services. Information which is more complex in nature or which fills a one-time, or limited, need can best be obtained from special studies. A practical minimum data set should be acceptable for the entire population in need of long-term care in all settings.

The data set which has been developed by the National Center for Health Statistics covers the following information areas:

- Personal identification---the assignment of a unique number to each individual in order to identify all records of service.
- Demographic information (sex, birth date, race-ethnicity, marital status).
- Personal attributes (usual living arrangements including institutional care, location).
- Court-ordered constraints.
- Health status (vision, hearing, expressive communication, receptive communication, and other indicators relating to interaction of the individual with his environment).
- Eight areas of function (including mobility and activities of daily living) in order to develop profiles describing the levels of dependency of groups of individuals.

This carefully defined and coded data set should make available to planners, policymakers, third-party payors, providers and others information with which they will be able to evaluate programs, compare costs, review service outcomes, analyze population needs, identify service requirements and compare alternative care systems. Each item in the NCHS minimum data set is defined, and the reasons for its inclusion and its anticipated usefulness are explicit. It should provide the long-term care field in general and Adult Day Health Care as a part of the field with information which will provide a basis for rational planning, evaluation and accountability.

RESEARCH

Research opportunities in Adult Day Health Care have been relatively limited. In part, this may be attributed to the fact that the services are new in the United States. In their development, Adult Day Health Care programs have presented such a wide range of purposes, objectives, and services, that it has been difficult to establish a frame of reference upon which reliable research efforts can be based.

Selected research efforts have been attempted. The most recent was funded in 1976 as a result of Public Law 92-603 (the "222" experiments). In 1974, a study of ten Adult Day Health Care Centers (the TransCentury Report) was conducted. A more limited study involved an analysis of a survey conducted by questionnaire.

The findings of the TransCentury Report substantiate general reactions in Adult Day Health Care: variety in the range of models, target populations, service "mix", staffing patterns, and differences in costing. Further program development, experience, and clarification will be required in order to identify those areas of information which are central to the field on which useful research efforts can be based.

Research issues will acquire greater usefulness when many of the basic questions identified in conference discussions (planning, purpose, population, organization and administration), have been more precisely addressed. The NCHS long-term care data set and special studies which may be developed to meet planning and program needs will contribute substantially to the field of knowledge. At this time, however, further research to consolidate "what is now known" about Adult Day Health Care could provide guidance to communities involved in planning efforts. Funding of such efforts at the national level would substantially assist in such planning efforts.

SERVICES, FACILITIES AND TRANSPORTATION

Services

At any given time, the service program is defined by combinations to the population served, the purpose (or purposes) of the center, and the individual service needs of the participant group. Changes in the participant "mix" and participant status require adaptation in service emphasis and, in some cases, changes in the program itself over time.

Using the concept of a dependent or semi-independent population whose need for care is based upon a combination of various disability levels and limitations in the personal support system, decisions concerning service emphasis range and intensity becomes a task requiring continuing analysis of the requirements in any given center of the participant population or projected population.

The process by which the service complex is established is determined by defined admissions criteria and the application of multi-disciplinary assessment and care planning. For example, a relatively large proportion of participants with mobility limitations may require a range of services emphasizing treatment as well as greater emphasis on the provision of physical support services. A relatively large proportion of participants with chronic illness may require health monitoring, attention to medication, and observation of changing health status.

Structured approaches to service emphasis in all programs are essential. "All participants in Adult Day Health Care have some impairment. It is important that the services which are provided fit participant need. This cannot be a casual decision but should be based on precise and factual information about what is needed and service capacity."

The Conference discussions indicated that there is less confusion about services than has been assumed. Certain services can now be considered common to all centers. As a minimum, the service complex should include:

- Nutrition services - the provision of one or more meals, and nutrition counseling.
- Health services - at a minimum, health supervision and health counseling which are reliable and "more than a casual nursing visit."
- Recreational and social activities planned for the levels of need of the participant group.
- Information and valid referral services.
- Social services integrated in assessment, care planning, counseling, and interaction with home and community.

Services which may not be common to all centers are those which emphasize treatment: nursing care; therapies (physical, occupational and speech); special diets; and personal care. Special programs such as education, remedial training, sheltered employment and art therapy broaden the service range and reach special participant requirements and interest.

Transportation

Transportation received considerable emphasis in both conferences. Transportation is a high-cost service in most centers. The use of family, neighbors and friends to transport participants to and from the center has been viewed as a stimulus for involvement in the center program and to help motivate the participant and/or the family:

- "I don't believe in providing transportation for all participants unless it is the only way to get them there. Family and neighborhood resources are a tool which help people stay more independant, and if you provide services indiscriminately, you take over family responsibility. The more we encourage family responsibility, the more cooperation we get from families in other treatment areas."

An opposing view has also been expressed:

- "Transportation is limited and expensive, particularly for participants who are in wheel chairs; 50% of our participants are in wheel chairs and live with working relatives; 20% have spouses who can't drive. Transportation is essential for all of these participants."

- "Research on family responsibility indicates that family members do not abandon their impaired relatives. When the menial and routine pressures are removed, families do not withdraw. On the contrary, objective evidence indicates that the quality of family interaction then improves."

Many providers who administer small, single programs do not consider transportation a major problem. In a state network, however, the range and cost of transportation present massive problems. These were identified as depending upon such considerations as the number of communities served by a single center, distances in the area of population covered, participant volume, variation in attendance, the degree of family involvement, availability of community provided vehicles, availability of specially equipped vehicles, availability of private special-needs transportation, program ownership of vehicles and resources available for the coordination of a variety of transportation methods.

- "A sound transportation plan is crucial to the success of an Adult Day Health Care program."

- "A great deal of rationalization is prevalent concerning transportation. Administrators find it difficult to confront the fact that their services are not accessible to the people who may need them most."

It was generally acknowledged that transportation is a high-cost item in Adult Day Health Care. In some centers transportation may be almost equal in cost to some levels of treatment, and this may increase the per diem cost substantially. Although cost is a significant problem for center programs, the absence or limitation of adequate transportation for the disabled is an issue which extends beyond the Adult Day Health Care center movement. It presents serious problems to many other populations, community resources and services as well. Communities which have been most successful are those which have developed special-needs transportation involving use of equipment for multiple purposes. This would include provision of transportation to various community agencies, to congregate meals centers, to clinics and physicians' offices, to special recreation and shopping as well as to Adult Day Health Care. Such arrangements require a high degree of coordination.

- "Transportation can be directly considered programatic; it is a policy and administrative matter and the alternatives can be understood and recommendations made concerning the virtues and disadvantages of different methods without waiting for the answers from research."

A positive approach to provision of transportation is based upon assurance of program accessibility: "A good program must be assured of accessibility to its services; transportation must be available; it must be safe and it must be reliable."

- Standards and regulations should include appropriate transportation as a requisite in Adult Day Health Care. Appropriate transportation is intended to include vehicles for special needs. Centers accepting participants in wheel chairs should be required to provide vans or buses which are adequately equipped. Transportation personnel should be screened for the same qualities and temperament as other center personnel and should be trained and capable of responding to participant needs, to emergencies, and/or other exceptional occurrences.

Discussions of safety extended to the personnel employed in providing transportation. Drivers and attendants must be carefully trained in transfer activities, first aid, and capability in emergencies. They must also be familiar with the program and sensitive to participants and their responses. "The service package should be defined as beginning when the driver arrives at the participant's door. The driver, therefore, must be in tune with the center's program goals. Transportation is an integral part of the service."

Facilities

Adult Day Health Care centers have been housed in a variety of settings, many of them not initially intended for their programs. A number of centers have been created in nursing homes, in some instances as an extension of the in-patient facility. In a very limited number of programs housed in nursing homes, the service has been used as a combined transitional program for in-patients, as well as serving participants from the community. Still other programs have used in-house settings which are independently administered units making use of available space and occasionally, but not invariably, using the institution's treatment facilities.

Questions have been raised concerning design requirements: space, equipment, safety and accessibility. The lack of definitive information in this regard has underscored the need for specific research on these matters as well as square footage per participant, relative costs and cost trade-offs when institutional settings are selected. The use of nursing homes and other institutional settings raises questions concerning the effect of the setting on participant attitudes. Institutions offer such advantages as barrier-free space adapted to individuals with a variety of impairments, and, in some instances, available back-up staff for treatment which might not be available in a freestanding setting.

On the other hand, participant and community reactions may consider a center in an institutional setting as service delivered in a "medical model", or, as related to stereotypes associated with long-term institutions. Self-perceptions of participants as "patients" or as involved in a care sequence which might end in an institution are factors which may affect the selection of the setting.

Adult Day Health Care Centers are also housed in recreation centers, multi-purpose senior centers, churches, unused hospital space, and, in some instances, in specially-constructed facilities.

It was generally conceded that a variety of settings is probably both realistic and desirable. Within this broad framework, however, the physical requirements of the setting and the cost-related elements which affect the selection of the setting must be considered. In addition to practicality and cost, a primary factor in the choice of setting should be community and participant attitudes.

The general requirements of the physical plant in all settings which may be considered adequate can be identified:

- All centers must be designed or adapted so that they are easily accessible for both wheel chairs and walkers whether or not state and/or local regulations require such access.
- Minimum fire and safety precautions must be assured whether or not state and/or local regulations require them.
- Barrier-free space should be a requirement in all centers serving participants with mobility limitations.
- Safety equipment (grab bars, railings), passage ways and doors must be adapted to the characteristics of an impaired participant group.
- Toilet facilities---"toileting is a sensitive area and must be stressed in services for disabled, impaired, or elderly people." In many centers not initially intended for day care purposes, toilet facilities have not been appropriately adapted. Such facilities should be constructed or adapted to insure easy access for wheel chairs and walkers, space and equipment for transfer, and protection of privacy. New construction should consider the ratio of facilities to participant group size (England requires a toilet for every 20 feet in new day hospital construction).

The choice of setting - institutional or freestanding - may become a major issue in planning. The lack of available space, the high cost of desirable space, urban population concentration, rural distances, and similar characteristics affect the choice of setting.

An arbitrary approach which indicates that one setting is preferable to another appears to be undesirable as a requirement in view of the very good programs which may be found in both institutions and freestanding facilities (and some quite poor programs which may also be found in either). Setting per se does not insure excellence in the quality of the services.

There is room for research concerning the elements which make a setting desirable or undesirable. An institutional setting might provide staff and facilities which make the choice desirable. "The important thing is to find a place with a splendid staff and leadership committed to the program. This makes the difference." This is not always possible, and the availability of space in an institutional setting may not counteract negative reactions on the part of participants. The assumption that such a setting is a "health setting" is not invariably supported by excellence in service delivery.

Increasing opportunities may appear for utilization of vacant space in hospitals as hospital occupancy rates decline, releasing barrier-free space with the possibility of back-up staff and equipment. Offsetting the advantage of merged costs of equipment and overhead in hospital settings is the fact that costs of space in hospitals are still a good deal higher than in other settings. Moreover, elements of Adult Day Health Care which are unrelated to treatment (social services, recreation, etc.) might be less available in these settings.

> It is essential that all settings provide for the Adult Day Health Care program a staff, space, participant population and service combination which is distinct, and that its goals are understood to be directed to the provision of a distinct care modality. "The Adult Day Health Care center must have identifiable space and identifiable staff."

STAFFING AND TRAINING

Attitudes and convictions concerning staff qualifications and the importance of professional services vary. Some providers report excellent results using staff composed almost entirely of paraprofessionals, stressing personal temperament and on-the-job training as primary qualifications (viewed as more acceptable to participants than staff with professional qualifications).

Other providers expressed the conviction that adequate assessment and goal-oriented services depend upon qualified staff in key aspects of the service.

> "Whether a center provides medical, nursing, social therapies in a package or selected combination, depending on community need, the staff in each

> category will have the background (in selection, training and experience) which has been generally accepted as constituting the protection of quality in that profession or category. While the amount of staff time required by the center's population may be open to question, the adequacy of the staff time allotted to that population may not be open to question. Given the determination that there must be a matching of services to participant need and that these services must be adequate in quantity and of good quality, the issues that remain open are still those related to: (1) how the ideal service package is to be determined; (2) what conditions that decision; (3) how staff/patient ratios will be established; (4) how these fit with a changing or varied or segregated participant population."

Staffing and training can be approached in a context which establishes objective criteria:

> "Staffing pertains to the quantity, qualifications and distribution of staff providing the services, and staff training will include staff orientation, in-service education, on-the-job training, off-the-job training, and general principles of staff development."

Staffing and Program Goals

In general, and in spite of differences in program emphasis, Adult Day Health Care centers do share common goals. The general objectives of the services may be expressed in different service combinations with varying service emphasis. They do, however, impose the requirement that all staff must possess certain attributes, some of them difficult to describe objectively, yet central to the quality of the services. Terms such as flexibility and empathy were used. "No matter what discipline the staff comes from and no matter how good the training program is, there are certain innate qualities of tolerance and flexibility which are absolutely essential." Staff members must be endowed with the ability to be satisfied with very small increments of change not necessarily basic to their techniques; the kind and nature of the demands made upon them are varied and quite different from those found in other care settings. Minor mannerisms, the tone of voice, the choice of language, can be of great importance. To some extent, understanding can be provided through training, but most of it will have already been present in the individual. "Compassion isn't enough. It may in some forms be a disadvantage."

The selection of staff and subsequent training will depend very much on the quality of program leadership. It must be strong, committed and knowledgeable and capable of providing essential back-up.

In training efforts, one of the disadvantages has been the absence of a comprehensive core training program. Formal training in the various professional fields from which staff members are drawn should be supplemented with training directed to the special requirements of Adult Day Health Care. One of its major ingredients is reliance on a multidisciplinary approach, regardless of model. There is - or should be - an intertwining of disciplines and/or a crossing-over of functional staff lines. As a result, "turf" problems may arise and the training program must take these factors into account.

The special characteristics of both Adult Day Health Care and Home Care require constant interaction between staff, participant, family and community, and the blending of services to meet both health and social need. Arbitrary distinctions in these areas cannot be made. These considerations require more expertise than is required in the provision of care from a single discipline. Such expertise does not occur without a methodological approach to training in both the core program and on-the-job training, and this applies to all staff who will be involved in any way with the participant and his family.

The team concept has been repeatedly stressed in Adult Day Health Care. Understanding of team composition is beginning to change. In place of a hierarchy which is fairly rigid, a more practical approach (often called matrix management) appears to be both effective and practical. At any given time, one, or perhaps two, people will be providing care services, although the resources of the entire team are available. The participant is assigned to a primary professional who coordinates the care which has been agreed upon with both the participant's approval and in accordance with staff recommendations. The primary professional is always aware of what is happening and becomes the single source of information to family and others. There must, however, be structure in this approach that is neither casual nor accidental; it must permit changes in the team in accordance with changes in participant status. When this occurs, responsibilities are shifted on a planned basis.

In the light of these requirements, there is an urgent, present need for the development of a core training program specific to Adult Day Health Care.

Staff/Participant Ratios

Determination of the number and kinds of staff as they relate to the range of participant needs has been a general problem in the field. A precise and clear-cut method of determining staff/participant ratios was described:

- An analysis of participant "mix" and the service needs based upon admission criteria, assessment and care planning.
- Development of precise staff job descriptions based upon participant population. These descriptions include task analysis, identification of the tasks that each staff member performs.
- Length of time required for performance of tasks based upon time studies, observation and objective "job logs" (these provide information concerning the optimum or minimum number of participants requiring skills or tasks which can be served by a given staff member).
- This information provides the base upon which averages can be developed: the average number of individual treatments, the average number of group treatments, the average number of assignments to each staff member, and, consequently, the number of treatments and participants for which staff of a given size can be responsible. On the basis of this information, the size of the staff needed for any given number of participants can be determined. The method justifies the staffing pattern; it

> also provides an opportunity to compare individual staff performance objectively. If the participant requirements exceed the ratio, this is an indication that service quality is being reduced.

In discussing this methodology, it was recognized that it may be necessary to experiment in the initial phases of program development. The methodology is easier to apply with a larger staff; availability of a small staff may require reduction in the participant population, or if participant need does not justify full-time staff, part-time staffing may be provided using the same methodology.

COST, FUNDING, REIMBURSEMENT

Cost containment is a common objective in health care services. In Adult Day Health Care it is not possible to support the conclusion that costs are greater than or less than other types of care and such conclusions would be questionable since the services are not comparable to other care modalities. Studies to date have not demonstrated that costs are excessive; they have indicated a range of costs in programs with different service emphasis. The issue of cost containment has, however, been an initial motivating factor in some program development. In one state, the initial objective was to develop Adult Day Health Care as a low-cost "alternative." "There was pressure to provide the services only to those who have been in nursing homes or discharged from hospitals." This approach was effectively counteracted with data indicating that Adult Day Health Care costs in the state were not excessive.

Concerns which are more prevalent are related: to service funding which will ensure continuity; to problems with multiple funding sources; and to the variety of reimbursement practices which impede effective administration.

One of the program examples which illustrates the history of funding a financial base describes an established center attached to a rehabilitation hospital. It was developed as a day hospital and later multi-level services were added. Federal funding was obtained initially for an innovative demonstration program (Medical Services Administration and the Administration on Aging). When the demonstration (3 years) ended, the center turned to the community for continued funding and support. Success in this effort was attributed to several factors: the program was responsive to community need and appropriate to the resources of the institution in which it was based (although a majority of the referrals came from the in-patient facility); the institution had long experience with rehabilitation services and continuity of staff; the administration had considerable expertise in developing and costing the service unit and in obtaining reimbursement for services. At the present time, the center relies on multiple reimbursement sources; 13 insurance carriers, Titles XVIII and XIX; fees from families; fund-raising and donations. Interpretation to both participants and the community of the complicated reimbursement arrangements is both difficult and confusing.

Reference is frequently made to the "skewing" of the service model to meet reimbursement sources, and to management strategies geared to the splitting of the service unit for reimbursement purposes. The excess manpower and complex administrative problems which this practice entails affects program development. It arises from the limited approach to service development and funding which has been repeatedly cited.

Cost effectiveness as an objective is addressed in terms of the need for measures of appropriate costs for various levels of care. "Although the same number of personnel is available in nursing homes, day care relies more heavily on skilled staff and therapeutic staff - the cost is high."6/ - a reference which again tends to compare the Adult Day Health Care with Nursing Home Care as if they are intended to serve the same populations and thereby offer services directed to similar goals. This confusion in purpose affects program development. "Adult Day Health Care has emerged in the United States in the absence of explicit financial provision in public policy for distinctly adding such an element to the health care system. Against the fiscal odds impeding their greater development, Adult Day Health Care programs have grown in number. The phenomenon of this growth in a financially-uninviting environment, even more than the impressive persistence of the underlying concept itself, attests to the apparent validity of grafting day care onto the social health care continuum."

Funding problems are attributed to the absence of basic recognition of the need for the development of the services and the fact that there has been no earmarking of funds for these services by Federal, state and local authorities. Programs attempt, with varying success, to secure funding from the following sources:

- The Medicaid programs of one-third of the states permit reimbursement - not for day care in its entirety, with the exception of a very few states, but for specified health services given within day care programs to individuals eligible for Medicaid.
- SSA Title XX Social Services Funds are used to reimburse day care programs in two-thirds of the states - again, by no means on an open-ended basis.
- Revenue-sharing funds have been used for day care in one-third of the states.
- Medicare nationally pays for those health services that are specified in its benefit packages for those eligible, and day care programs can seek certification to be reimbursed for providing such services under the specified conditions. (This is done in a very limited number of programs.)
- Private health insurance carriers likewise may be billed for covered services for their subscribers.
- The Older Americans Act, through several of its titles, makes some funds available through grants to selected programs.

- Some United Way funds in various communities subsidize day care programs.
- Philanthropic support from foundations, church, fraternal, and similar private organizations and individual patrons on occasion come into play.
- Some local public funds are sometimes channeled to day care support.
- Several Federal agencies grant funds in support of research, demonstration, and evaluation of relevance to these agencies (e.g. transportation, mental health, training, etc.)
- Fees are collected from the participants themselves.

"With this variety of opportunities seemingly to be tapped for support, the very range of possible sources reflects the fragmented provisions that characterize this country's health services."

At the point of delivery, this multiplicity of funding sources imposes an overwhelming burden on providers. It also reduces accessibility to the services of unknown, but probably sizeable, numbers of potential consumers for whom substantial expenses for inappropriate care now being made could be reduced, and for others who are not receiving care of any kind in spite of serious levels of impairment.

Discussions of appropriate funding emphasize the elimination of means-tested access and suggest approaches more closely aligned with equality of entitlement for vulnerable populations. This approach is one which presents Adult Day Health Care as a legitimate care modality, no longer innovative, with demonstrated effectiveness. "The services should be institutionalized as a universal service in the community support system and publicly funded."

Two separate but concurrent efforts are required in order to make the services universally available: (1) Capacity building (capitalization for creation of the resources) - "the day of demonstrations and seed money is over" - and a planned approach to the development of services, probably on an incremental basis which will make such services available to the population at risk is necessary. Such funding would most properly be identified in the long-term care budget. (2) Development of effective reimbursement methods or mechanisms---a problem which is prevalent throughout the entire health care delivery system. "Fee-for-service reimbursement is not a reliable or equitable basis for the support of the services."

Some exploration is required relative to funds for capacity building. The feasibility of combining existing funding sources for all long-term care services including Adult Day Health Care would have advantages as an integrated system of providing financial support for an inclusive service package. A second possibility (less probable in the present economic environment) is appropriation of adequate funding designated for Adult Day Health Care. In the discussion of the relative advantages and disadvantages of categorical versus comprehensive funding, balanced funding for long-term care is considered the most desirable objective.

However, the relatively brief historical position of Adult Day Health Care might place it at a disadvantage in competition with other established services. The need for manpower and training funds and provision for service evaluation and continuous monitoring in such an effort is evident.

Current priorities in research in areas of costs are those related to the development of unified cost accounting and reimbursement mechanisms, methods for channeling multiple-source funding into an integrated funding system, studies of the effects of funding on levels and quality of care and of the effects of funding on service combinations with different service participant groups and in different locations and settings.

- Consideration must be given to the adoption of a clear national policy for the development of Adult Day Health Care services in the community care system with necessary provision for financing and implementation of such a policy.

STANDARDS AND REGULATIONS

"Although standard, rule and regulation are frequently used interchangeably, a standard is usually defined as something established by general agreement to serve as a basis in measuring capacity, quantity, etc.

"Rules and regulations tend to be used interchangeably and in tandem in government circles. Although rules and regulations may serve as guides, criteria or standards, they are more frequently used in the sense of requirements, obligatory or demanded as a condition.

"Rules and regulations might be defined as musts, while standards might be defined as shoulds."

These distinctions have not usually been made with reference to Adult Day Health Care services. There is, however, a need for assurance of consistent services and accountability. If this is a need for standards, what should their purpose be for the field? If this is a need for regulations, should they be met by all providers for purposes of reimbursement or should the purpose be protection which guarantees observance of overall objectives and purposes of the services, regardless of reimbursement source? (Regulations, when they are established by government, contain elements which may protect the public; they may also be requirements limited to reimbursement or essential for licensure.)

The development of standards has more frequently occurred in the voluntary service sector, in professional fields of practice, in commissions, as goals of excellence which may or may not be achieved but which establish optimum measures of quality.

An illustration in the development of standards at the state level describes a program developed as a state network (3 centers growing in number to 13 in a relatively-short timespan) which began without standards or regulations, adopted the "222"* framework as a temporary measure and, with the enactment of enabling legislation listed required services and defined a need for basic standards which "would ensure that all people were receiving basic core services and that the people receiving the services were being provided with appropriate care."

Standards "lay out a framework against which programs may be implemented with appropriate regulations." Standards may be viewed as "principles which assure quality, as guidelines, as minimum requirements which specify what is essential or as optimum objectives to be achieved in incremental steps." A long-range approach is necessary in the establishment of a standard framework: "We would like to develop the optimum measure of excellence in the programs. We recognize the fact that as programs grow, certain elements will be developed which may incrementally come close to the optimum. We are working toward an objective of quality and this does not necessarily take into consideration what the state will do today or what the Federal government will do in the future. We would like to build a framework within which we can see some kind of expanding future." Standards or principles should include key elements which are essential to the services. Included as essential are; architectural requirements; barrier-free space which is identifiable; accessibility; adequate staff services and administration which are also identifiable; established staffing patterns and training methods; and purposeful goal-oriented services. Narrow standards or principles are a danger: "They become so rigid that it is not possible to incorporate new experience and new knowledge as we learn more about the services."

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* Described above, Public Law 92-603, Section 222, mandating demonstrations for the purpose of testing Adult Day Health Care and Homemaker Services.

Because many levels of government as well as other public and voluntary groups are (and should be) involved in service development, participation in the development of standards, principles, and regulation should include these groups.

QUALITY; QUALITY ASSURANCE

Factors which affect quality in services have been described in the previous sections. Those which are subtle are possibly difficult to identify - leadership, commitment, interpersonal relationships, ambiance - others are measurable and have been described under three headings: Input Measures, Process Measures, and Output Measures. These were outlined as follows:

> Input - What is available for provision of the service? (It is taken as given that the providers have good intentions.)

1) Is there trained staff to deal with an older population (the services described were related to older people), e.g. R.N., M.S.W.? This training deals with add-on education which is specific to the participant group.

2) Are there sufficiently varied programs in the facility so that there is a match between the client and the services? (Is there a varied "menu" of service?)

3) Is there a minimum length of stay and goal orientation?

4) Is there a blurring between professionals as the various professionals broaden their professional discipline? (Does each professional only do his own professional work or is he able to do other professional work?) This is a requisite for a team approach. (The physician should not always be the team leader.)

5) Is there a data system that is valid, reliable, relevant to the issues concerned with in that facility and is it portable? Does it cover other programs?

Process - What goes on in the program to foster quality of care?

Criteria of Process:

1) The evaluation should be comprehensive and form

the basis for the design of individually tailored treatment, rehabilitation and re-socialization programs.

2) Approach to re-evaluation - at some specified interval the program should be changed if you are doing something. Is there re-evaluation of treatment goals and reassignment of treatment modality?

3) Is there a case management approach? You must be aware of what is in the community since no single program offers everything.

4) Does the initial evaluation include the eventual home environment to which the person may wish to return or be rehabilitated, e.g. stairs, stove, the availability of a social network which may be nascent or which must be created?

Output

Measures of Output:

1) Measurement of any change in functional status of the individual. Improvement is not always a necessary outcome; with quite disabled populations, stability or slowing of the deterioration may be all that can be expected. The participant should be able to show change over time. Criteria for such change might be greater autonomy, better mental and physical health and self-care capacity.

2) Re-integration into the community. This may occur in many forms.

3) Self-perception of the individual - Graduation as a model for other patients to other levels of care or as a visible model of how improvement can occur.

There may be a need for research in some areas which will produce objective measures of quality. There is, however, already substantial agreement on service quality in areas which may be considered common to all programs:

- Planning and development. The service program is designed to fit designated population need rather than funding sources.

- Admission criteria. Clearly defined as to the population to be served and the services provided with assurance that there is a reasonable "fit" between the two.

- Provision for program change. "If it is determined that service need has changed, there must be willingness to change the program accordingly."

- Service objectives. The services provided are based upon recognition of the overlapping problems which exist in impaired or disabled populations. Attempts to make distinctions between "social" need and health need are avoided:

  > "The presence of disability or impairment carry an implicit assumption that the need for services will involve consideration of multiple factors and demand a service emphasis which responds to this multiplicity. Both health content and social content are quality requirements."

- Auspices. Who can do the best job? "It is not a question of deciding for or against a given auspice. We must discover the advantages and disadvantages of different auspices. There are enough programs in the field at the present time to make evaluation between auspice, populations served and service adequacy possible. This information should not be directed to the elimination of any given auspice but rather to indicate advantages which may be maximized and disadvantages which should be avoided."

- Setting. Physical setting considered in practical terms. Attention to ambiance. "There is a common assumption that people who are disadvantaged economically are uncomfortable in settings that have aesthetic quality and this has been used to rationalize the placement of some programs in dismal settings because they are cheap and available. There is ample evidence that the response to the environment has a positive relationship to treatment outcome."

- Staffing and training. The necessary qualifications of staff are already well-known to experienced providers. Staffing patterns and training methodology have also been developed. Provision of well-prepared, adequate staff is a major guarantee of service quality. "If there is not sufficient money to provide adequate staff, the size of the participant group should be reduced accordingly. There is a level below which staff ratios should not be reduced."

- Policies and procedures. The range, duration and intensity of services are based on established procedures for assessment, care planning and evaluation.

- Coordination. Routines are built into the internal service system and extended to related community sources in a structured manner. "The assumption that coordination will occur spontaneously is not valid." There is a methodology which extends beyond the will to cooperate.

- Consumer participation. Consumer participation goes beyond the consumer and his individual care plan. It includes established channels enabling consumers and families to affect program policy and practices.

- Community participation. Established methods for interpretation and re-interpretation exist. Channels for community response are established.

- Data Collection and Evaluation. A data system for purposes of service planning and evaluation is established. A common goal in addition to service data should emphasize longitudinal analysis identifying special attributes of the population served, the services and results of care in order that planners, providers and the public will be reliably informed.
- Standards and Regulations. A broad framework outlining principles for quality services is established in order to assure that regulations reflect a concern with quality in the services more closely.

SUMMARY

Adult Day Health Care Services have increased numerically in the United States in recent years. With this increase, there is an evident and growing need for clarification of the purpose of the services, the populations which they are best adapted to serve, service combinations which are most effective, and methodology which will maximize their effectiveness. In all of these areas, there is variation in programs. The establishment of consistent practice will support service quality and enhance public understanding. Some aspects of service development will depend to a considerable degree on research.

The Arlington-Tucson Conferences attempted, in reviewing the present status of the field, to establish a framework within which reliable present knowledge could be identified and researchable issues delineated - an approach directed to eliminating unnecessary vagueness where possible and consolidating a practical base for future inquiry and reliable service development. In the discussions which took place in two conference sessions separated by an interval of one year (September, 1977 - September, 1978), the same subject areas were addressed: the variety in program emphasis (service models); services and facilities; staffing and training;

service delivery patterns; planning, organization and administration; cost; evaluation and research; standards and regulations; quality assurance. In the first session, however, the format was one which involved substantial numbers of participants from a wide variety of programs and interests and, in the second, a smaller group which could effectively examine the results of extensive discussion in greater depth in order to establish present status and indicate future direction.

Most discussion began from an awareness of the variety in existing program approaches and this appeared to limit consideration of a common knowledge base upon which consistent program development could occur. However, the Arlington Conference presentations and discussion as well as the closer examination undertaken in Tucson indicate commonalities in virtually all programs. The populations to which the services are directed and the purpose and definition of the services appeared to be primary to consideration of many of the questions raised concerning Adult Day Health Care such as service models, standards, staffing, training, and costs.

A framework considered sufficiently broad and flexible describes the population for which Adult Day Health Care is most appropriate as including dependent or semi-independent adults* who, because of functional impairment combined with limitations in the personal support system, are in need of services which restore and/or maintain optimum health and function in a setting adapted to this method of care.

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* There is general agreement that day health care services are appropriate for all age groups; there are, however, special service characteristics which separate services adapted to children and adolescents from those provided to the adult group.

The appropriateness of the services and the emphasis in service provision are determined by the needs of the participant group and are based upon assessment by qualified multidisciplinary professionals.

Staff selection, preparation and training are based upon established methodology; selection emphasizes tolerant and flexible personal characteristics*; professional training meets the standards of the individual discipline; and on-the-job training for all staff, including paraprofessionals and all other staff, provides special knowledge and skill required by the special characteristics of Adult Day Health Care.

Service composition and staff-participant ratios are derived from a continuing analysis of service plans following participant assessment and the capacity of the staff to schedule treatment and related activities. Geographic problems and manpower resources may alter the potential of centers to offer a full range of full or part-time services and this may in turn affect the capacity of a given center to accept participants requiring services which are unavailable.

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* Special characteristics of Adult Day Health Care which affect staffing have been identified. The capacity in staff for acceptance of such elements as slow increments of change in participants, the crossing-over on a planned basis of professional and paraprofessional skills, a team concept which is flexible in structure are among those which require special approaches to staffing.

Services basic to all Adult Day Health Care were identified: health care; nutrition; social services; recreation and social activities; information and referral; and transportation. Those services which may not be common to all Adult Day Health Care and are provided on the basis of participant need or special program emphasis include treatment (therapies) and such programs as vocational training and sheltered employment.

Settings in which the services are placed may vary, but minimum requirements include space and activities which are clearly identified as reserved to Adult Day Health Care; barrier-free space accessible to wheel chairs and walkers; provision for privacy; access to emergency back-up and other needed services with formal arrangements for such care; a comfortable and cheerful physical environment.

Implementation will be achieved in the following ways: Planning, organization and administration follow accepted practices considered essential to all community services. The services are provided in response to valid community need and are perceived and accepted as such. They are intended for a designated population rather than to meet an available funding source. They are integrated into the structure of community services with formal arrangements for referral and participant movement through the community system. They are realistically funded. Administrative structure guarantees accessibility to the services and makes provision for clearly-understood admissions criteria and admissions procedure based on assessment of assured quality. Policies are established which clearly define the range, intensity and duration of the services.

There is provision for consumer and community participation in the service program. Effective data collection systems are adapted to program evaluation and are also aligned with data collection in state and national systems - an effort which stimulates program comparison and broad approaches to program development.

Standards and regulations, which are frequently considered interchangeable, are not universally available or consistent at the present time in Adult Day Health Care Services. Regulations are frequently more closely aligned to reimbursement requirements than to population need. The establishment of guidelines as the base upon which national standards can be built can probably best be achieved at the Federal level with the participation of those providers and communities in which there has been substantial service experience.

Funding, reimbursement and cost containment are problems for present providers and for program development because of the multiplicity of Federal, state and local funding sources with differing program requirements. The variety of approaches to funding and reimbursement in different states and the absence of consistent methodology related to reimbursement and to cost analysis are barriers to effective program development. Experienced providers do not yet have a channel which will make possible the pooling of such information for broader use.

These problems and concerns are reflected in all areas of Adult Day Health Care. There is a strongly-expressed need for an office or central authority at the Federal Level which will establish national policy, pool existing information, provide leadership in the development of services of good quality, initiate action which will simplify and unify funding and reimbursement, and provide for equitable treatment of the populations for which the services are appropriate.

Adult Day Health Care is considered a vital component in all long-term care services for which this suggested Federal approach is essential. Their development as an important service in the continuum of care system is dependent upon consistent Federal and state approaches in order to maximize effective use of existing resources and broaden individual and community options in the choice of appropriate care.

RECOMMENDATIONS

A. Conference recommendations on which there was substantial agreement:

1. The development of Adult Day Health Services in the

United States has progressed sufficiently to justify national recognition of their value as a component in community health care systems.

2. Their status requires a national policy with the investment of funds for planning, technical assistance, program development, training and evaluation, and research.
3. There is an evident and pressing need for a focal administrative unit at the Federal level for all long-term care services, but particularly for non-institutional community services in order to broaden care options at the service level and make effective use of national health care funds.
4. The inclusion of Adult Day Health Care in an integrated Federal approach to long-term care will maximize the effectiveness of other services.
5. There is a pressing need for a comprehensible and comprehensive restructuring of funding. Rational integrated funding and reimbursement practices at Federal and state levels should be directed to minimizing inequities and unnecessary costs in manpower in the present system.
6. Equitable treatment of populations in all areas of the U.S. with respect to service entitlement should be a major objective.

B. Provider-consumer issues produced substantial agreement in the following areas:

1. The title "Adult Day Health Care" appears to be an accurate description of the services. Agreement on a title which is universally employed will increase public understanding and support.
2. Establishment of service purpose - to restore and/or maintain optimum health and functional status where functional impairment and limitations in the personal support system require health, social and support services - should erase artificial distinctions between "health" and "social" purposes. The purpose statement recognizes the comprehensive and changing needs of a population which is functionally impaired, dependent and/or semi-independent.
3. Consolidation and distribution of materials from the field is now possible. This material includes effective core training programs; data collection methodology; staffing methods; cost analysis systems; guidelines for standards and regulations. This effort, assumed as a Federal responsibility, should have highest priority in order to assure consistent practive of good quality in the developing field.

C. Major areas requiring study and research:

1. Estimates of population requiring Adult Day Health Care Services.
2. Manpower requirements for the provision of Adult Day Health Care of good quality.
3. Studies of space requirements for participant groups of different size in programs with different service emphasis.
4. Studies of optimum requirements in program setting.
5. Methodology for integration of uniform long-term care data systems and Adult Day Health Care program records.
6. Effective uniform methods for funding reimbursement and costing of Adult Day Health Care (Federal-state-local).

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PROGRAM

ADULT DAY CARE CONFERENCE

Arlington, Virginia September 27-29, 1977

INTRODUCTORY REMARKS

Ted Koff, Ed.D., Associate Professor, University of of Arizona - "...and it came to pass..."

Edith Robins, Deputy Director, Division of Long-Term Care, Bureau of Health Services Research/DHEW

VARIATIONS IN ADULT DAY CARE PROGRAMS

1. Restorative - Mr. Loy Veal
2. Maintenance - Ms. Marie Louise Ansak
3. Psychosocial - Ms. Miriam Zatinsky
4. Satellite Programs - Mr. Gordon Purdy
5. Network - Ms. Brenda Siqueland

DISCUSSION

HIGHLIGHTS OF SPECIALTY AREAS

1. Organization and Administration - Mr. Hadley Hall
2. Planning - Dr. Ethel Shanas
3. Staffing and Training - Ms. Brahna Trager
4. Services, Transportation and Facilities - Ms. Eleanor Cain
5. Quality Assurance - Dr. Eric Pfeiffer
6. Regulations and Standards - Ms. Virginia Hart
7. Cost Containment - Ms. Ruth von Behren
8. Reimbursement and Funding - Ms. Charlotte Hamill

LUNCHEON

Speaker: Mrs. Bernice Harper, Director, Division of Long-Term Care, Health Resources Administration/DHEW

Program (Continued)

STATE-OF-THE-ART AND RESEARCH IMPLICATIONS

Dr. William Weissert, Ph.D., Division of Intramural Research, NCHSR/DHEW

DISCUSSION

DAY CARE EXPERIMENTS AUTHORIZED BY PUBLIC LAW 92-603, SECTION 222(b)

Ms. Eileen Lester, Deputy Chief, Research and Development Branch, Division of Long-Term Care, Office of the Administrator, HRA/DHEW

DISCUSSION with Panelists

Ms. Charlotte Hamill
Mr. Hadley Hall
Mr. Robert Mack
Phillip Weiler, M.D.
Mr. Nitin Mehta

GENERAL SESSION

Opening Remarks - Ms. Edith Robins
Policy Issues - Part I - Ms. Edith Robins
Policy Issues - Part II - Ms. Eileen Lester

OPEN DISCUSSION with Panel

Mr. William Oriol
Dr. Ethel Shanas
Ms. Sandra Fischer
Ms. Eileen Lester
Ms. Brahna Trager

NOMINAL GROUP PROCESS AND CONFERENCE OBJECTIVES

Dr. Peter Orleans

Program (Continued)

GENERAL SESSION

Strategies for Follow-up - Dr. Jerry Solon

PRESENTATION of Nominal Group Process Recommendations

Dr. Peter Orleans, et al.

DISCUSSION of Vote for Final Recommendations

Dr. Ted Koff

CLOSING REMARKS

Ms. Edith Robins
Dr. Ted Koff

PROGRAM

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Tucson, Arizona September 19, 20, 21, 1978

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ADULT DAY HEALTH CARE: FAMILY PERSPECTIVE

by

Edith G. Robins

Adult Day Health services are appreciated and enjoyed not only by the users of the services, but also by the caretakers of the recipients -- those who must make the hard decision to institutionalize the individual or to provide the supportive care to keep the loved one at home. Just what Adult Day Health Services means to the caretakers was graphically described at a panel discussion held in conjunction with a workshop on Adult Day Health Care in September 1977 sponsored by the program in the Champaign County Nursing Home in Champaign, Illinois.

Mrs. Ruth Shankin, Administrator of the program, was the guiding force behind this workshop, and Mrs. Allan Steinberg, daughter of a Day Care participant, chaired the panel discussion. Permission was generously granted by all participants to reproduce the discussion, and a follow-up report as of May 1979 was provided to give added dimension to the facts presented. (The verbatim transcript was edited to provide consiseness.)

The panel represents a cross section of the population from the vantage points of ages, relationships, socioeconomic and ethnic backgrounds. The discussion reveals the problems faced, the progress made, and the various ways people came to the program. If as is often said, statistics are facts with the tears wiped off, this discussion graphically portrays the real problems faced by disabled individuals and their loved ones, and the happy solution provided by the Adult Day Care Program. A report of the costs prepared by the Champaign County Adult Day Care program presents the hard facts on the cost-effectiveness of these services as they view it.

The Champaign County Day Care Program provides a blend of intensive restorative services for participants released from hospitals and maintenance care for those who have achieved maximum function. It is carried out in separately identified quarters in the nursing home, by a staff specifically assigned to this task. Participants pay their own way or are assisted by "scholarships" made available through donated funds. No Federal, State or County support has been provided for this program.

The panel participants were as follows:

Mrs. Allan Steinberg, Chairman
Mrs. Leslie Belew
Mrs. Robert O. Barbre
Mr. Richard Chaffee
Mrs. Narbey Khachaturian
Mrs. James Scott

Mrs. Steinberg: I guess mine is a pretty typical family -- three children, a dog, a cat -- and one extra that maybe not too many middle American families have -- we have Grandma. Grandma came to live with us about five years ago. She is over 80, and she is my mother. We cannot leave her alone because she is disoriented much of the time...and I know that my mother, even in her most disoriented situation is very concerned that she has her own home. The time arrived when we realized that this was going to be a major problem -- we would have to find full-time live-in help or full-time day care. It was then that we heard about this program.

But before I describe our experience, I thought you would like to hear about the backgrounds and experiences of some other consumers of the program, their family situations, and their needs for this kind of care.

Mrs. Barbre: I was thrust into needing this care for my husband very quickly last fall after he had an amputation. I knew about the program because I live next door to the Day Care Director. Fortunately, the program has a bus that picks him up in the morning. I work as a registered nurse, and this meant that I could go on working.

I can't say enough good things about the program -- it's something no one will really understand unless they, like me, could keep a loved one at home instead of having to place him in a nursing home for full-time care.

Mrs. Belew: My husband is disabled and has been for six years. Until a little more than a year ago, he was at least able to walk around and talk -- but then he had a stroke, and more strokes. Then he could not do anything for himself. The Day Care program has been the answer for us...otherwise, I could not have taken care of him because I too am disabled. When he comes home from the Day Care program, his disposition is so different than it was when he had to lie sick at home all the time.

But I do have a problem -- finances. I can't afford to pay for the Day Care program. My church agreed to pay, and I began to get help from some of my relatives, even though it was hard for them...I hope someway, somehow, other people will be helped through Day Care as I was. And I hope one day all people who need it will get Day Care rather than be put in a nursing home. I appreciate all that has been done.

Mrs. Khachaturian: We are also very grateful for everything that has been done by the Day Care staff for my mother-in-law. Almost every day, she'll call me in the afternoon and say, "Oh, I had a very good time today with my friends." We never find out just what she has done -- but we know she has enjoyed it!

She came to this country fifteen years ago. Since she is now 82, that means she was about 67 when she came. She didn't know the language, and so it was difficult for her to make friends. She depended greatly on my husband (her son) for everything through the years. It was difficult. We heard about the program through an article in the newspaper. We didn't need the program at that time, but I remembered it.

Then the time came. My husband's mother had gotten out of a nursing home following a second hip fracture — and she was totally disoriented. She literally didn't know what century it was. We were fortunate in finding someone who would stay with her in her apartment twenty four hours a day, so we were able to take her out of the nursing home. In short order she improved, and did not want anyone in her apartment. It was at that time that we found the Day Care program.

Mrs. Scott: My mother is originally from Kentucky. She came here about two years ago — because of confusion, she could no longer take care of herself. For about a year, we were able to have her stay in her own home which is a mile from us, with me just going over several times a day, and with her coming to our house.

But with my two small children, that wasn't easy.

I found the Day Care program to take care of mother during the day, and I found a woman who needed a place to stay to serve as her companion during the evening. I go in and do the cleaning.

Sometimes a problem arises when the lady wants to travel to her hometown. At such times, my mother participates in the overnight part of Day Care. Then in the daytime, she goes to the program.

Usually, one day a week is all she needs.

Mrs. Steinberg: How did you hear about this program?

Mrs. Scott: By word of mouth. I have a couple of friends who worked part-time at Champaign County at one time or another, and they told me about it. When you are looking for help you go through all this calling — you call fifteen people you know, and everybody knows somebody else that you could call and you spend hours upon hours on the telephone.

Mr. Chaffee: My wife had a severe stroke about four years ago. She was receiving therapy at Mercy Hospital, and I found out about the Day Care program from them. So I decided to try and keep her at home. This is a very difficult situation because she cannot talk. Because of her severely impaired condition, I had to make a decision either to try to get help this way or to put her in a nursing home full time. Through the help and understanding provided by the Day Care program, I have been able to keep my job and work and keep my home together.

Mrs. Steinberg: Mr. Chaffee, I think the group might be interested in knowing about your dinners and how the program helps you out that way.

Mr. Chaffee: Yes, the program has been a lifesaver to me. I couldn't have gone on without it. I would have had to put her in the nursing home on account of my work. Because I work every day, I couldn't work and leave her home because she cannot stay home by herself.

Mrs. Steinberg: I was alluding to the fact that Mr. and Mrs. Chaffee both stay a little bit later and have dinner at the nursing home and then go home, so that he doesn't have that obligation too.

I think we touched upon the referral sources that we all use — hospital social services, public health nurses, word of mouth, and the Office on Aging.

This program has meant so much to all of us here. In my mother's case, each morning she says, "I'm going off to work." In fact she really doesn't remember what she has done all day. If I ask her, she'll tell me that she went to work and she did what they told her to do and she made hats. Fifty years ago, my mother made hats when she went to work. And we just leave it at that. I think it is just the sense of being part of the activities of life and have a routine which has greatly benefited my mother and so many others also. I think, Mrs. Belew, you might want to talk a little about how your husband has improved in the program.

Mrs. Belew: My husband has been a different person since he has been attending the program. Before that time, he was frustrated and very, very hard to get along with. When he goes to Day Care, he is happy when he comes home. He does not remember the things he does, but he knows that he enjoys whatever it is he does. And he tries to tell me as much as he can, but he can't talk very well. In other words, it is just the answer for both of us.

He has greatly improved since starting the program. He is able to walk better. And he is beginning to talk better. At times, he can say most anything he wants to say. Before, he could hardly be understood. And so I think that this is the answer for us.

Mrs. Steinberg: I asked Mrs. Belew, because some of the staff told me that when Mr. Belew started the program he couldn't walk and he couldn't talk — and now if you happen to be in the center while he is there, you see him pushing somebody else and really actively doing the things he couldn't do before.

Mrs. Khachaturian, would you care to comment?

Mrs. Khachaturian: My mother-in-law is new in this country, and did not have friends — now she feels she does have friends, and that makes her happy. She participates in activities, and assists in passing out coffee cups. She always enjoyed being a hostess, and this makes her feel as though she is having friends in for coffee.

Mr. Chaffee: When I first brought my wife home, she was so disoriented and frustrated that she didn't even want to accept her own home. By being able to take her someplace and get relief, her attitude has improved tremendously. She still has a severe impairment and she cannot talk — but you just don't know what it means when a person does not accept her own home!

Mrs. Scott: Mother never wants to go to a nursing home. If I drive by Champaign County and she sees the nursing home, right away she says, "I don't need to go there." I see the Day Care program as sort of a halfway point. It's the softening of the blow for her and for me when and if the time comes when we cannot take care of her any longer.

Mrs. Barbre: When Mr. Barbre first started, he was in need of physical therapy. He didn't have his prosthesis at the time. One of the big things for us is not having to take him to the hospital for physical therapy.

Mrs. Steinberg: I am glad you mentioned that. I think an important part of the Day Care program is the ability to give all the needed physical therapy and other rehabilitation services in one place.

Three years ago, I didn't know I had certain friends —

but now I know that the Day Care staff are some of my best friends. The quality of staff in the program is indescribably wonderful — Jackie, and Vince, and Mrs. Ettensohn to mention a few. They view their task as not only taking care of the users of the program, but of the families as well. Many times I have spoken with Mrs. Ettensohn about our concerns. Her guidance as well as some of the literature she has given me have really helped to console me. Apparently I am in one of the most difficult situations with three adolescent children and Grandma in one house. This tends to pull one in many directions. It is comforting to know that I fit into a certain category and that people understand how I feel — I can't properly express how important that service has been. I have someone who understands and can sympathize and help me.

I also know that my mother relates to the quality of people who care for her — and she is pretty fussy. I've seen the van and I've seen how they help her get on and off the van, and most importantly, I've seen how she relates to these people. She doesn't relate to many people — but these are very important people to her, and I can't stress enough how marvelous the quality is.

I might just mention the overnight capabilities of the program. I know that Mrs. Scott has used it for her mother on occasion. For us, it has been marvelous that we could take a weekend and know that Grandma was O.K. I remember the first time I picked her up after a holiday — she just flurried around and got her things and said to the nearest person, "I am going home now because I do have a home you know." And I think that's just a little bit of insight into how important this program is.

As with any marvelous program, I guess there are things we would like to have that are not provided at the moment. Would anyone want to comment on some unmet needs?

Mrs. Barbre: I need the service on Saturday and Sunday, because I have to work on weekends.

Mrs. Khachaturian: The weekend care would be welcome. My husband has had the responsibility for so long of helping his mother in her apartment, that the strain is beginning to show. On weekends, he has to go and fix her food. We live out of town, and it requires constant driving. We have tried bringing her to our house for Sunday dinner and that's fine during the meal, but five minutes after dinner is over, she starts wanting to go back to the apartment. She is extremely restless, and this has really been a big strain on us.

I wish there were more of a way to make the elderly people feel needed.

On the days that my mother-in-law does not come to the program, the meals-on-wheels program has also been an enormous help. The woman who owns the house puts it in the refrigerator, and my husband heats it up in the evening.

Mr. Chaffee: There was one period of time when my wife was in the nursing home. After she came home, a student nurse came to our home and helped my wife put a meal together. My wife can't cook any longer, and she even forgot where things were in the kitchen. This was a pilot project, and the nurse worked with her for six weeks, and it did help a little bit. Such retraining would take a lot of time and patience, but perhaps it could be undertaken in the future.

Mrs. Steinberg: Mrs. Belew, does your husband use some other social agency?

Mrs. Belew: Yes, in the beginning, my husband went to Threshold and he enjoyed it very much because he was able at that time to walk around and communicate. But that was only for short term treatment - such patients had to be able to work again, and he won't ever be able to work. Then the Lodge came into being, and he was changed to that program. That program was also helpful. But a year ago, after he had his last spell of sickness he wasn't able to attend the Lodge any more because he could not take care of his needs. He needs help in eating and in going to the bathroom. Day Care provides all that help and that is why it means so much to us.

Mrs. Steinberg: Both Threshold and Lodge are outpatient mental health facilities -- halfway house programs.

Another aspect of the program we should touch upon is cost. For a number of us, it's the biggest bargain in the world. For some others, it is more than can be handled. For example, Mrs. Belew can only afford a few days a week because of the cost.

Mrs. Belew: I was very concerned about being able to find funds not only for my husband but for many other people who I know who would like to attend the Day Care program. I wrote a letter to Governor Thompson explaining my interest in other people's needs, and my own problem because I knew our financial arrangement is not permanent. As of October, the church will no longer pay for my husband's Day Care, and I am searching for funds so that my husband can continue to go and I can keep him at home with me. He hates hospitals and nursing homes. And I want him to remain a part of our home as long as possible. The only way we can do that is if someone will come to our aid with funds to help him to continue to go on.

Mrs. Steinberg: Mr. Chaffee, do you have any comments about the cost of the program?

Mr. Chaffee: This program enables me to work and keep our home together and keep us financially solvent. If I didn't have the Day Care Center, I'd have to put my wife in a nursing home full time which would mean more expense. This would cost me quite a bit and make a big difference in my finances. After a while, this would drain my savings and I would become insolvent.

Mrs. Steinberg: For a number of us, Day Care is not only an emotionally satisfying route -- it is also an economically beneficial one. However, there are a large number of people who cannot even afford what I consider the low cost of the program we participate in. I think we as consumers need to write letters to our legislators to make it possible for those who are eligible for Title XIX and Title XX to receive reimbursement for Adult Day Care services, and to see if we can't get money for the funding of more programs of this kind.

...I think the simplest way we could say "thank you" to the program is to say this: "It has saved my life."

FOLLOW-UP REPORTS 1 YEAR AND 8 MONTHS LATER (MAY 1979)

Mrs. Steinberg's mother, Rita Gerletz, has remained physically stable. She continues to ambulate unassisted, and needs supervision only with activities of daily living. She has had recurrent episodes of gout, and has visited her doctor in his office every few months. The family situation remains unchanged -- working parents with teenage children, a very busy household, and a strong desire to keep their grandmother with them. Occasional overnight stays have been provided by the Day Care program for Mrs. Gerletz when the family is out of town. Mrs. Gerlitz attends the program 5 days a week; reality orientation and socialization are the most important components in her treatment plan.

Mr. Barbre has had 2 hospital admissions since the Conference. He was admitted 10/19/78 for pneumonia, following a 4 day trip to Missouri. He was discharged from the hospital 11/20/78, and returned to Day Care the following week. Again on 2/18/79 he had an overnight hospital stay. His wife continues to work as a nurse and he attends Day Care about 3 times a week. He ambulates with assistance and a walker, and gait training is still part of his treatment. His mental alertness is much improved.

Mr. Belew was hospitalized 2/9/79 with a stroke. He now ambulates with assistance, receives gait training and therapy for improving all activities of daily living skills. his alertness has increased, and he can express himself with a limited few words. Scholarship funds are necessary to keep Mr. Belew in the Day Care program, as the combined family income is less than $300 a month, including SSI. He attends the program twice a week.

Mrs. Khachaturian attended the program until November 1978, when she was hospitalized with pneumonia. At that time, because of her weakened condition and severe mental deterioration, she was admitted as an inpatient in the nursing home for long-term care.

Mrs. Scott's mother, Mrs. Agnes Rehm, was in Day Care from 3/23/77 until 10/24/77. At that time, she was admitted to Champaign County Nursing Home's Long Term Care program for Intermediate Care. She died on 3/28/79.

Mr. Chaffee had a heart attack on 6/13/78. While he was hospitalized, his wife was admitted to the nursing home shelter care program. He was admitted to the nursing home during his recovery period. Both were discharged on 8/17/78 and returned home. Mr. and Mrs. Chaffee then started to attend the Day Care program. Mr. Chaffee requires the program because of his special diet needs as well as the need to monitor his blood pressure and pulse; Mrs. Chaffee receives speech therapy, and her condition has basically been unchanged.

SUMMARY OF 1978 ACTIVITIES

CHAMPAIGN COUNTY ADULT DAY CARE PROGRAM

1978 monthly average; 350 client days, 250 transportation units

Served 86 different clients in past 3 years.

85% discharged to LTC
10% expired at home or in hospital
5% discharged — 1. Program no longer needed
2. Discharged out of town
3. Service not effective

4.5 years longest Day Care Service

8 months average Day Care length

2.5 days per week, average days of service

Of the present total enrollment of 32
75% would qualify skilled in LTC
22% would qualify intermediate in LTC
3% would qualify shelter in LTC

Referrals
70% families
20% Hospital Social Services
10% other agencies and Doctors

Largest number of problems encountered are in area of transportation
1. Weather
2. Bus maintenance
3. Time involved
4. Scheduling
5. Ramp at homes for wheelchairs

Most common needed procedures
1. Medications
2. Bathing
3. Beauty and Barber services
4. Ambulation
5. Bowel and Bladder training
6. Feeding assistance
7. Catheter changes
8. Dressing changes and soaks
9. Blood tests

DAILY COST BREAKDOWN

Administration	$ 1.96
Indirect Services	1.14
Phone	
Rent	
Insurance	
Direct Services	
Staff (Coordinator, 2 Aides, Bus Driver)	6.81
Fringe Benefits	1.24
Contracted Professional Staff	2.58
Food	1.73
Supplies	.29
Transportation	1.00
	$16.75

EXCERPTS FROM LETTERS

"Day Care was great for us. Frankly I don't know what we would have done without it. It definitely prolonged the time Mother could stay in her own home. It helped her make the adjustment to living at the nursing home. She was able to paticipate in suitable activities and make friends. And I feel Day Care delayed the time before she had to go on Welfare. There is quite a difference between Day Care charges and the $800 plus a month for full time nursing care. I still strongly support Day Care at Champaign County and would enjoy having some of my tax dollars spent for such programs."

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"From the start of the Day Care program, my husband's alertness increased and he became more like his old self. He enjoyed seeing many of his old friends, and felt he was doing me a favor because I was able to continue in my job as a registered nurse in a local hospital."

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"...As for the Day Care Program at Champaign County Nursing Home, I cannot say enough about what they have meant to me and my wife. Without their help and understanding, I do not know what condition my wife and I would be in today. No one knows all the problems of this situation until it happens to you and your wife."

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"...As a working wife, mother of three adolescents, and daughter of and 80 year old woman, I have found this service of indescribable benefit."

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"My mother is forgetful, disoriented, and anxious, and simply cannot be left alone any longer. Yet, she still relishes her family status and her home with us. It would be a major setback to her self image were she forced to leave the family and reside in a nursing home."

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"Your Day Care program has been a Godsend. The ability to combine care and stimulation and companionship for an elderly citizen with the maintenance of family stability is a remarkable solution to our problem -- and also one of the most economical ways of handling the situation. In addition, the shelter care service has done a great deal for us in easing the burden of my mother's care. By being able to leave her for family vacations and short trips once in a while, our spirits are rejuvenated and we are once again able to care for her. I should add that the quality of your service is exceptional. We are so pleased with your superlative staff and the loving concern and care they offer."

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"Without the program I am afraid that my mother would have to be placed in a residential nursing home. This would be unfortunate — since it is so much more emotionally satisfying for her the way things are now, and so much more economical for her, for us, and I believe, for society. I do hope the County will see fit to continue the program and I will be happy to provide any kind of assistance I can offer in the provision of this excellent service to other County residents."

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NOTE: Illinois has not been providing reimbursement for Adult Day Care through Title XIX and has provided Title XX support on a very limited basis. However, the Illinois General Assembly is considering the appropriation of $2.5 million in State of Illinois General Revenue funds to the Illinois Department of Aging for Adult Day Care Programs.

MASSACHUSETTS ADULT DAY HEALTH SERVICES

Edith G. Robins
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Office of Standards and Certification
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In the four years since the inception in Massachusetts of the first Adult Day Health Program reimbursable under Medicaid, the program has sharply escalated. As of May 1978, 39 programs have been approved for Medicaid reimbursement, 35 of which are operational and serving more than 800 individuals; the remaining four programs are expected to start services in the summer months. Of the 39 programs, 10 are in non-profit nursing homes, 8 are in proprietary nursing homes, 16 are in free standing community based facilities, 4 in chronic disease hospitals and 1 in an acute hospital. It is also anticipated that additional programs will be approved in the coming months.

An indication of the acceptance of the program within Massachusetts is the fact that the prescreening procedure for applicants for nursing home placement or for home health services now requires that consideration first be given the potential of utilization of Adult Day Health services as a viable alternative services before other placements can be approved.

Inclusion of the 1978 narrative report of Massachusetts in this publication does not imply official endorsement of all the facts included; rather it is intended to facilitate a sharing of information for all who are concerned with program development. For more specific information about the Massachusetts program, inquiries should be addressed to:

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ADULT DAY HEALTH SERVICES
MASSACHUSETTS MEDICAL ASSISTANCE PROGRAM
YEAR END REPORT FOR FISCAL YEAR 1978
(JULY 1, 1977 - JUNE 30, 1978)

I. INTRODUCTION

Background

Between February 1975 and January 1977 the Massachusetts Medical Assistance program (Medicaid) awarded six contracts to nursing homes, hospital and community providers to operate adult day care centers in the Commonwealth for a one year pilot study. The major factors prompting Medicaid to enter into the adult day care pilot study were:

- Increased attention to a wider variety of service options within a continuum of care.
- Federal initiatives in the area of adult day care and other alternatives to institutionalization.
- A greater awareness on the part of policy makers that from both a quality of life and fiscal standpoint it was no longer desirable or feasible to rely only on the institutional model to meet the needs of a growing chronically ill population.

The Concept

Although new to Massachusetts, adult day care was not a totally new concept either nationally or internationally. Psychiatrically oriented adult day care began in England as early as 1940. That country as well as the Scandinavian countries in the 1950's expanded the day program concept to serve the physically impaired and socially isolated client. In this country, in 1972, amendments to the Social Security Act authorized HEW to initiate pilot day care programs for Medicaid and Medicare eligible clients. Basic federal guidelines were drawn up to govern these experimental programs. These guidelines allowed the possibility of three very distinct models of day care to emerge:

- the therapeutic or restorative model; designed primarily for the short term rehabilitation client.
- the maintenance model; designed for the chronically ill or disabled client who needed health supervision and socialization to maintain his/her functional status.
- the social model; designed for the frail elderly who needed socialization and supervision but who had no specific health needs.

In Massachusetts it was felt that a merging of these various models would be more appropriate both for the pilot study and the apparent needs of the population. As a result, guidelines were developed which were more specific than the general Federal guidelines to govern the six pilot programs. The major components of the Massachusetts day care programs were:

- health restoration, monitoring and supervision
- social service counseling for program participants and their families
- therapeutic recreation and socialization
- personal care
- nutrition
- transportation

Staffing guidelines required that the program have an R.N. for a minimum of two hours per day, an activities director for a minimum of four hours per day, occupational, physical and speech therapy consultants and an overall staff/participant ratio of one to six.

It was decided to allow programs to accept both private paying as well as Medicaid eligible clients. The major criteria for acceptance to the program was based on the client's eligibility for Level III nursing home placement.

It was hoped by Medicaid staff and the pilot programs that adult day care would:

- be an alternative to or delay premature institutionalization
- offer respite during the day to family caretakers
- prove to be a cost-effective service option

The Evaluation

A report published January 27, 1977 entitled "A Study of Adult Day Care Centers in Massachusetts" by Catherine M. Smith, Jeanne Lucero and Hazel Croy, R.N. evaluated the first year of adult day care in Massachusetts. The report demonstrated that the program had achieved its goals, seemed to be cost effective and was a viable and needed service option in Massachusetts. In addition the report showed a high degree of client and family satisfaction with the program. It was felt by many of the clients and their families that this was a program that could meet several of their needs within one setting as opposed to having to obtain piecemeal service from other health and social service programs.

Expansion

The results of the pilot evaluation encouraged Medicaid to expand the number of adult day care* programs in Massachusetts. The pilot guidelines were revised (the most notable changes being an increase in the minimum staff/nursing requirement to four hours per day and the insistence that program sites should be barrier free for the handicapped), a request for proposals disseminated to interested providers and an inter-agency task force developed to review and approve incoming proposals. During Medicaid's fiscal year 1978, eleven new adult day care programs began operating in the Commonwealth.

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*The name Adult Day Care was formally changed to Adult Day Health Services in June 1977.

II. FY'78 REPORT

This report will focus on the following areas of adult day health based on data accumulated from the 17 programs in operation during fiscal year 1978 (FY'78)

- Population Profile
  - A. admissions
  - B. discharges
  - C. functional disabilities
  - D. diagnoses
  - E. social information
  - F. other services in addition to adult day health
- Program Information
- Transportation Information

The following narrative will first summarize the program and population aspects listed above. The charts which follow this narrative describe in more specific detail, by program, each of the areas discussed. We will conclude this report with a brief summary and five month update. An appendix to this report should be published in February 1979 listing complete cost information for each program.

III. NARRATIVE SUMMARY

POPULATION PROFILE

A. Admissions - 336 new clients were admitted to adult day health programs during FY'78. 52% of these admissions were referred from health related facilities and organizations. 22% were referred from Home Care Corporations and other community social service organizations. 14% were referred by family, self, or friends, and 4% were referred from some other source. In comparison with the pilot year, we see an increase in health organization referrals. This increase is reflected largely and significantly in an increase in referrals from hospital discharge planners. Hospital discharge planners make the bulk of nursing home referrals, yet seemed reluctant to refer to adult day health programs in the early stages.

A large part of the discharge planner referrals was made to programs which were part of the original pilot project. This suggests that longevity of a program counts in establishing itself firmly enough to attract this type of referral. The second largest block of health organization referrals come from the Visiting Nurse Association (VNA). The VNA has access to many clients who would be appropriate for day health services. It is interesting to note that the highest percentage of VNA referrals was made to free standing community based adult day health programs as opposed to nursing home based programs. There was a large increase from the pilot year in the number of referrals made by Home Care Corporations and other community agencies. There was a sharp drop from the pilot year in referrals made by family. This suggests that adult day health is becoming more widely accepted in the community health/social service network as a viable service option and an integral part of the continuum of care.

Each of the clients admitted in FY'78 as in the pilot year was deemed at risk of Level III or Level II nursing home placement by Medicaid staff.

B. Discharges - Of the clients discharged in FY'78 (106): 37% were discharged to institutional care; 15% went to skilled nursing facilities (SNF); 17% to intermediate care facilities, 2% to chronic hospitals and 3% to rest homes. In many instances those discharged to ICF's and rest homes would not have had to be institutionalized if there were a stronger family support system for evening and weekend care. It is interesting to mention that a large percentage of those discharged to institutions were discharged from nursing home based adult day health programs. This is most probably explained by two factors; (1) generally speaking, nursing home based programs seemed more willing to accept a sicker clientele; (2) many of these programs took clients only as emergency respite for families until a nursing home placement could be found. There was absolutely no evidence that nursing home based programs were using adult day health clients as a means to fill empty beds. Many of the clients discharged went to different institutional facilities. It should also be noted that the transition from community to nursing home seemed much easier for those who had become more familiar with the institutional setting in an adult day health program.

6% clients relocated - in over 50% of these cases adult day health staff arranged for their transfer to another day program both within and out of state (as far as Florida).

6% of the clients died.

42% of the participants were discharged to the community - this does not mean, however, that 42% of the participants got better. There were several reasons for this type of discharge. 29% of the clients were either afraid to come or did not feel comfortable. Fear was caused primarily to traveling in winter weather. People were uncomfortable for a variety of reasons. Family members often pushed the client into the program unwillingly; two people had a language barrier problem; two felt too young; one woman was embarrassed by incontinence on the way home in the van. More than 90% of those clients discharged, because of fear or dislike remained in the program for less than one week. There was no indication that the program site, free standing or nursing home based, caused dislike. 5% of this population was discharged because of disruptive or abusive behavior to other clients. There were few if any other resources in the community to help these clients although some agreed to mental health counseling. Transportation difficulties caused the discharge of another 3% of the clients. Moving in with family caretakers alleviated the need for ADHS for another 3% of the clients, while 5% of the clients despite problems of their own had to leave the program to take care of other family members. 6% of the population, unfortunately, had to leave the program because they could not afford it. The absence of little, if any, funding other than Medicaid for Adult Day Health Services is perceived by both the Medicaid program and individual program staff to be a big drawback in accessing participants from the community who need care. On the brighter side, 14% of the clients discharged to the community had improved after their stay in the ADHP and were discharged to more independent living situations. Thirteen of this 14% were referred to and participated in Senior Center programs in their community. One person was placed in a paying job. To ease the break from the ADHP many of these same participants returned to the program one or two days a week as volunteers.

The ADHP staff in all cases tried to arrange appropriate referrals for those discharged to the community. 40% were referred to Home Health Agencies for nursing or aide service; 24% were referred to Homemaker services; 10% were referred to mental health services; 6% to hospital rehabilitation clinics; 3% to family service organizations; and 3% to congregate housing; 3% of the discharges replaced ADHS with private duty nursing or a hired companion.

C. Functional Disabilities - The following functional areas were surveyed to determine the degree of disability in each of the areas among day health participants.

- mobility
- walking
- bathing
- stair climbing
- dressing
- feeding
- toileting
- wheeling

In four of the eight areas surveyed (mobility, walking, stair climbing, and bathing), over 50% of the day health admissions were to some degree disabled. 41% needed assistance in dressing, 23% in toileting and 17% in feeding. 20% were wheelchair bound.

In comparison with the pilot year participants there was a slight increase in disability in the areas of ambulation, dressing and bathing. There was a huge increase in the number of wheelchair bound participants, emphasizing the importance of the barrier-free requirement. There was a substantial decrease in the number of participants requiring assistance with feeding.

The nursing home-based program overall had a more disabled population than the community free-standing programs, although the percentage of the disabled at the Dorchester, Holyoke and Cambridge programs were very close. There was significantly higher disability in nursing home-based programs in the areas of dressing and toileting as well as a significantly higher proportion of wheelchair bound clients.

The lowest percentage of disabled clients were in the Lynn, Chicopee, Roxbury and Brighton programs. This in part is probably due to the fact that these programs have fewer facilities for the disabled in terms of bathing facilities or physical therapy equipment.

Overall about 5% of the population was incontinent. In almost all instances of incontinence, however, the programs had bladder retraining classes in effect.

D. Diagnoses - While multiple diagnoses are prevalent in an aged or disabled population as a whole, we felt it would be useful to list the diagnoses of day health participants to emphasize some of the serious health disorders among this population which indicate a need for nursing care and monitoring. The top nine diagnoses overall were not suprising considering the population and were as follows:

Hypertension - 26%

Arthritis - 17%

Congestive Heart Failure - 9%

Diabetes - 19%

Depression - 16%

Arterio Solerotic Heart Disease - 8%

CVA (Stroke) - 18%

Angina - 7%

Chronic Brain Syndrome - 7%

As is evident from the above listed diagnoses as well as from experience, one of the most important functions of the program R.N. is one of observation. Hypertension for example, in and of itself, is a serious health problem which can lead to stroke or heart attacks. With careful monitoring and observation of the hypertensive participant the R.N. can do much to avert the possibility or at a minimum be alerted to the imminent stroke or heart attack.

E. Social Information - The social information charted dealt with the age, sex, housing and living arrangements of the day health participant admissions. Not surprisingly 79% of the population was over the age of 60. Of that percentage, 46% were 75 years of age or older. Less than 3% of the population was under 30 and the rest between 30 and 60 years of age. While the majority of persons served are elderly it is imperative to note that this service model can be just as relevant for a younger chronically ill and/or disabled population. We are currently seeing a growing number of referrals of clients in the thirty to fifty year age group.

54% of the population were apartment dwellers, 7% lived in Senior Housing, 33% lived in single family homes, while 1% lived in rooming houses, congregate housing or other housing.

Surprisingly, 40% of the participants lived alone, 23% with children, 21% with a spouse, 9% with a relative, and 1% with a friend or other.

In comparison with the pilot program participants the only major difference was the increase in the number of persons living alone. It should be noted that almost universally the day health staff expends a great deal more effort for those clients living alone. These efforts range from coordinating better housing, homemaker and home health aide services to grocery and clothes shopping and laundry.

35% of the admissions to adult day health in FY'78 were male, 65% were female.

F. Other Services in Addition to Day Health - In addition to the services received in the adult day health program we surveyed additional therapy, home health and homemaker services received by participants on admission and to the general adult day health population in June, 1978.

We found that of those admitted in FY'78, 19% were receiving physical therapy, 7% were receiving speech therapy and 13% were receiving occupational therapy. These figures dropped somewhat when a survey was done of the overall population in June. At that time 13% were receiving physical therapy, 3% speech therapy, and 8% occupational therapy. The admission figures correlate with the high degree of disability demonstrated and the high occurrence of participants admitted who had a stroke. The drop in the June figures correlates with the fact that Medicaid as well as other third party payers will only reimburse for a limited number of direct therapy treatments. Follow-up therapy done by day health staff increased from admission figures ot the June figures.

In terms of home health and homemaker services, 15% of the population on admission were receiving Home Health (VNA and/or home health aide) services only, 21% were receiving homemaker services and 8% were receiving a combiration of home health/homemaker services. With the exception of a drop from 8% to 3% in those receiving combined homemaker/home health services there was no signigicant change in the number receiving these services in June.

Homemaker services cannot be performed by adult day health staff (e.g. housecleaning). It is therefore logical, especially considering the high percentage of participants who live alone that 21% if not more should be receiving these services. We are often questioned as to why day health participants require home health service in addition to day health service. Day health participants are receiving such service for a variety of reasons:

Examples

- a person who attends the program two days a week but is a diabetic who cannot self administer insulin may need a VNA nurse to administer the insulin the other five days.
- a person who requires adult day health services but cannot get dressed by himself/herself in the morning without assistance may need a home health aide each day to assist in this activity.

While the Department carefully monitors to assure non-duplication of services we recognize that a combined package of services (day health and others) may be necessary to meet an individuals needs.

PROGRAM INFORMATION

With expansion of the program the number of persons actually being served has doubled in one years time. The daily capacity for service has increased from 103 slots per day to 400 slots per day. The potential number of slots overall, given that average attendance is 2.7 days per week, has increased from 150 slots to approximately 600 slots. Actual enrollment has not kept up with the potential number of slots for several reasons:

- the relative newness of so many of the programs (no new program opened until 6 months into the fiscal year and several opened 9 months or later into the fiscal year).
- reluctance upon the part of other agencies to refer clients until the new program had proven itself.

Significantly 69% of the clients were Medicaid eligible. While some of this may be attributed to the effects of poverty on health it is probably more relevant that Medicaid is the major funding source for the program.

While 2.7 days was the average scheduled attendance for each enrollee, 2.3 days was the average number of actual days. Programs could figure on each client on average being absent 2/5 of a day per week. Therefore if a program had twenty clients a day scheduled, one or two clients on an average would be absent each day. With the exception of the Holyoke program the heaviest absences were shown in the community based programs. For Medicaid clients absence due to illness was double absence due to other reasons. For self-paying clients absence due to illness or other reasons was about the same.

TRANSPORTATION

Each adult day health program has a transportation provider number with Medicaid and can draw on a variety of resources for securing adult day health transport. Such resources range from private transportation companies, to having their own program vehicles to maximizing on community transportation resources. Medicaid always encourages programs to use the lowest cost, appropriate means of transportation. Programs that have the least difficulty in transportation are those programs which have their own vehicle or contract for transportation services with one provider. Those experiencing the most difficulty are those who are coordinating the use of several transportation providers (up to twelve in one instance).

However, the data demonstrates that overall the programs are securing relatively low cost transportation services.

15% of all trips taken were by taxi]
7% of all trips taken were by chair car] most costly

36% of all trips taken were by program vehicle]
30% of all trips taken were by community resource] low cost or free
12% of all trips taken were by family members]

Our best estimate on cost is that over-all transportation costs were $4-$5 round trip per person on average

MASSACHUSETTS DEPARTMENT OF PUBLIC WELFARE, MEDICAL ASSISTANCE PROGRAM, ADULT DAY HEALTH SERVICES—COST REPORT

INTRODUCTION

Although there are over 400 known adult day health and social service programs (generically known as adult day care programs) in the United States very few data reports have been issued on either the costs or other aspects of the program. This is probably due to the fact that many of the programs are still in the development stage and have not been in existence long enough and/or had the resources to generate such reports.

The Massachusetts Medicaid program sponsored six adult day health programs in 1975/76. Due to the success of these pilot programs expansion of the number of programs was initiated in 1977. As of March 1979 the Massachusetts Medicaid program has approved thirty-seven programs for operation in the State with thirty-two in actual operation.

In July of 1977 Medicaid requested existing and all new programs to submit monthly cost report forms to the Department. Although a flat per diem rate of $13.00 per person had been established to cover all program costs with the exception of transportation and direct therapy costs this rate was based on unsophisticated and perhaps inaccurate cost data. In fairness to both the providers of service and the Department it was felt that more accurate cost data would have to be collected to assess the validity of the present rate structure.

Because of the increasing number of inquiries the Massachusetts Medicaid program has had from prospective providers in our own State regarding the true costs of Adult Day Health Services and because of the Multitude of inquiries from both single providers and governmental agencies in several other states regarding the same issue we have used the monthly cost report forms to generate this cost report on adult day health services in Massachusetts.

It should be clearly understood that the Massachusetts Medicaid program through this report is not saying that all adult day programs nationwide should or will experience similar costs. Regional differences and differences in program models* may make the costs appreciably higher or lower in other states. For example, an intensive care and heavily staffed Day Hospital program is more than likely to exhibit a much higher per diem rate than any of the programs in this report. A lesser staffed program whose purpose is primarily socialization and minimum supervision conceivably should exhibit lower per diem rates than shown in this report unless such a program is in a state or region with higher salary ranges, food costs, utility costs, etc. than Massachusetts.

In this report the Department is merely trying to demonstrate what is felt to be the true costs of adult day health services in Massachusetts for a model which has been highly successful in meeting the combined health and social service needs of a population that is at risk of institutional placement.

PROGRAM SUMMARY

The costs of the following programs are listed in this report:

Program	*Site*
Amherst Adult Day Center	Nursing Home (for profit)
Therapeutic Day Care for the Elderly	Nursing Home
Don Orione Adult Day Center	Nursing Home
Community Day Care for the Elderly	Community Center
Lynn Adult Day Center	Multipurpose Senior Center
D'Youville Hospitality Center	Nursing Home
Cambridge Adult Day Center	Freestanding Center
Nevins Adult Day Center	Nursing Home
Holyoke Adult Day Center	Freestanding Center
Hollingsworth Adult Day Center	Nursing Home (for profit)
C&ROP Adult Day Center	Freestanding Center
Dartmouth Adult Day Center	Nursing Home (for profit)

COST APPENDIX—AVERAGE DIRECT AND TOTAL PER DIEM COSTS OF COMPARABLY SIZED PROGRAMS

Level of occupancy (percent)	Average direct cost per diem	Average total cost per diem
Programs with 15 participants per day		
100	$7.80	$13.08

COST APPENDIX—AVERAGE DIRECT AND TOTAL PER DIEM COSTS OF COMPARABLY SIZED PROGRAMS—Continued

Level of occupancy (percent)	Average direct cost per diem	Average total cost per diem
90	8.64	14.54
85	9.11	15.34
80	9.72	16.36
Programs with 21 to 24 participants per day:		
100	9.20	14.17
90	10.22	15.75
85	10.81	16.66
80	11.50	17.72
Programs with 30 participants per day:		
100	9.83	12.23
90	10.92	13.59
85	11.56	14.39
80	12.29	15.29

PROGRAM DEVELOPMENT COSTS

As Medicaid is a fee for service reimbursement agency the per diem rate funding is for operational costs only and does not take into account the initial costs necessary for the development of an adult day health program. Adult day health programs in Massachusetts must seek initial start up funds from resources other than the Medicaid program.

Due to the many inquiries however that the Department has had regarding start up costs we have summarized in this report the typical developmental costs experienced by the Medicaid approved programs in Massachusetts. In this report we have exhibited only the range of developmental costs and not the actual start up costs experienced by each individual program.

DEVELOPMENTAL COST SUMMARY

General costs

Most programs have found that due to initial cash flow problems and slow enrollment build up that a minimum of two months direct operating costs are necessary to cover initial salaries, consumables, supplies and overhead costs. Most programs also have added an additional three months salary for the program director so that he/she may be hired prior to program operation for organization and administrative purposes.

Two months of direct operational costs has ranged from $16,000 to $17,500 for a program with a capacity for thirty participants per day to $7,000 to $13,500 for a program with a capacity for fifteen participants per day.

Equipment costs

Equipment costs vary from program to program depending on the setting and participant capacity. Many program are able to obtain donations for many of the items required, thereby substantially reducing the capital equipment cost. Experience has shown however that whether donated or purchased the following minimum amount of equipment is necessary in starting a program:

Equipment	*Price range*
Furniture:[1]	
Large activity tables (for dining also)	$40–$100
Small game tables	$30–$60
Reclining chairs (1 for 5 participants)	$160–$240
Couch	$300–$500
Arm chairs	$40–$100
Table chairs	$15–$35
Coat rack/lockers	$15–$300
Storage shelves	$300–$200
Medical equipment:	
Emergency oxygen	$40–$60
Drug cabinet	$15–$35
Large scale	$100–$150

Small refrigerator	$165–$240
Nursing/personal care items (first aid supplies, foot basins, urine testing kits, blood pressure cuff, dressings, scissors, etc.)	$100–$300
Wheelchair	$160–$300
Office equipment:	
Desk(s), stationery, file cabinet, pens, pencils, charting records, etc.	$400–$700
Kitchen equipment:	
Stove	$160–$300
Refrigerator	$150–$350
Coffee pot	$30–$50
Miscellaneous	$20–$40
Miscellanous equipment:	
Housekeeping supplies	$15–$30
Activity supplies	$50–$100
Television (optional)	$150–$500
Stereo/radio	$160–$300
Miscellaneous costs: Advertising, postage, application fees, etc	$100–$300

[1] Department on capacity.

Note: The range for total initial equipment costs: $3,000 to $10,000 depending on the cost per item and the size of the program.

RENOVATIONS

This report does not cover any price ranges for renovation or building costs as they are so specific to each individual program. Approximately one half of our programs have experienced renovation costs ranging in extent from making one bathroom accessible to the handicapped to total construction of a day health center. It is worthwhile to mention that some programs have substantially lowered the labor cost of renovations by using the labor available from trade schools and technical high school programs.

In conclusion we can generally say that it is safe to assume that a program with a capacity of fifteen participants per day may experience start up costs ranging from $10,000 to $20,000 excluding renovation costs. A program of thirty participants per day may experience start up costs ranging from $20,000 to $40,000 excluding renovation costs.

It is important to reemphasize however that the range of costs reported here should be looked at as a guide rather than an absolute. Initial staffing, speedy enrollment, space and equipment costs, donations available, etc. are all unknown variables. The Department has seen one program with a capacity of twenty per day develop successfully on a shoestring developmental budget of $6,000.

REPORT SUMMARY

In summary the following may be concluded:

Based on the *total* program costs submitted by the centers surveyed in this report the average total cost per diem for all the programs is: 100 percent occupancy, $13.16; 90 percent occupancy, $14.62; 85 percent occupancy, $15.45; 80 percent occupancy, $16.46.

Transportation costs average $4.00 to $5.00 per person per day. Adding the transportation cost to the average total per diem cost we see the maximum costs for adult day health services ranging in average from $18.00 to $21.50 per person per day.

On Average 73 to 74 percent of the per diem cost goes towards personnel expenses, with 13 percent allocated to program expenses and the remaining 13 percent allocated to overhead costs.

70 percent on average, of the dollars represented in the total per diem rate are direct or actual costs to the adult day health program. The remaining 30 percent are inkind or donated costs.

It is important to note in this summary that while the figures represented in this report as total costs are those submitted by the programs these total cost figures are not necessarily all used in calculating the Medicaid per diem rate for adult day health services. The Massachusetts Rate Setting Commission is the governmental unit responsible for setting rates for Medicaid program services. They are mandated by law to base rates on fair and reasonable cost. The Rate Setting Commission would very likely delete some of the costs listed in this report when calculating a per diem rate. For example, if a program was overstaffed based on the Medicaid regulations of a one-sixth direct care staff ratio extraneous direct care staffing costs would be deleted when calculating a rate. It can be assumed that a new rate (soon to be established) would fall somewhere between the direct cost and total cost per diems listed in this report.

While all of the Medicaid clients admitted to the adult day health programs were considered by professional nursing staff to be eligible for Level II or Level III nursing home placement and with the average multi-level nursing home rate at $30.61 in Massachusetts it would seem based on the costs exhibited in this report that not only is adult day health a substitute service for institutional care but also a cost saving service in comparison. HOWEVER, to adequately compare institutional costs to adult day health costs it would be necessary to complete a much more in depth report than the one we have presented here. To reiterate, the intent of this report has been to exhibit the true adult day health costs in Massachusetts of a program that very successfully addresses the multiple health and social needs of its participants.

DAY HEALTH SERVICES TO NURSING HOME AND MENTAL HEALTH RESIDENTS

WASHINGTON STATE DAY HEALTH SERVICE PROGRAM

Washington State day health standards allow day centers to serve nursing home residents for a maximum of three months when it is a realistic goal to move the resident to a lower level of care within that time period. The original version of the standards prohibited day centers from enrolling nursing home residents, but this policy was changed to accommodate persons participating in the day health program who suffered an acute episode and had to go to a nursing home for a relatively short period of convalescence. The day center directors felt these individuals would have a better chance of leaving the nursing home as planned if they could resume attendance at the day center as soon as physically able. The three-month limitation was instituted because it was appropriate for persons expected to have a short nursing home stay and because the Department of Social and Health Services was concerned about paying a day center to provide services to a client for whom the nursing home was receiving payment for full-time care.

One day center also serves residents of the State Mental Hospital. In these cases the hospital pays the day center for services rendered and the three-month limitation does not apply.

The day centers have been successful in helping their own clients return to the community after a recuperative stay in the nursing home, but of even more interest is the success they have had in relocating mental hospital patients and nursing home residents who are not former day health clients. Some nursing home or mental hospital residents have been helped to move into a congregate care facility or adult family home and others have been able to move back with their families or even into an independent living situation.

Presenting problems of both nursing home residents and mental hospital patients are somewhat the same. Most suffer from low self-esteem and loss of faith in their ability to be independent and make decisions. They tend to be isolated and find it hard to form meaningful relationships. Most have some degree of depression and feel a sense of loss. Disorientation and confusion are common. Many nursing home residents have major physical problems, either a serious disability or a chronic illness.

Services provided by day health centers to help nursing home and mental hospital residents move to a lower level of care are varied. Wheelchair bound clients are taught how to transfer safely and to care for their personal needs. Occupational therapy, physical therapy, and speech therapy are provided as needed. Clients learn how to do rehabilitative exercises, understand the purposes and side effects of their medications, and relearn how to perform the activities of daily living. Day center staff help the client find a new living situation, arrange for needed services and become involved in community activities. Some clients receive individual or group therapy to overcome emotional problems and others are encouraged to more independent. Day center staff educate the client's family on the effects of the illness or disability and how to give the client necessary support without discouraging attempts at independence.

Day centers are most successful when assisting nursing home residents who do not require skilled nursing care and have not been in the nursing home for a long period of time, such as a year or more. A long period of residency in a nursing home tends to reduce the client's confidence in his or her ability to manage alone and some clients who initially express a desire to leave the nursing home change their minds when faced with the difficulty of regaining control over their daily lives. For reasons not fully understood, length of stay in a mental hospital does not seem to be as critical a variable as length of stay in a nursing home. Possibly this is because most mental hospital patients are in and out of the hospital, so even long-term patients have had occasional periods when they went back to living in the community. Both nursing home and mental hospital clients are more apt to succeed in leaving an institutional environment if they have the support of their physician, family, and friends.

Day health staff are convinced that more nursing home residents could move to a lower level of care if they could receive day health services for longer than three months. This limitation has caused them to terminate clients who were almost ready to leave the nursing home, but needed a little more time. Washington State will be examining its policy in this regard to determine if it should be more flexible and allow day health services to continue when there is clear evidence the client has made progress and is still a likely candidate for more independent living.

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